
***Tuberculosis patients' experiences of participating in
a DOTS program in the Copperbelt province of
Zambia***

Nina Holm



Supervisor: Ane Haaland

Co-supervisor: Mette Sagbakken

University of Oslo, Faculty of Medicine

Institute of General Practice and Community Medicine

Section for International Health



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Abstract

Tuberculosis patients' experiences of participating in a DOTS program in the Copperbelt province of Zambia

Introduction: Tuberculosis (TB) is a serious public health problem in Zambia. The long treatment (DOTS) patients have to undergo is challenging, and poor communication between TB patients and health workers in the DOTS program is in the literature described as a barrier to treatment adherence. There is little research on how patients experience participating in a DOTS program and on what the TB patients perceive as good and poor communication. More knowledge is needed on what patients perceive as problematic in the communication with health workers and what patients perceive as good communication.

Objectives: The main objective of this study is to explore how TB patients experiences participating in a DOTS program in order to better understand how communication in a DOTS program influences the patients. Specific objectives are to explore how patients seek and receive information, advice and care in the DOTS program, and to explore how patients are participating in decision making regarding their own treatment schedule.

Study design/methods: This is a qualitative exploratory study using semi-structured interviews, group interviews, focus group discussions and participant observation for data collection. A total of 37 TB patients participated as respondents in this study.

Findings: Patients who were followed up at home by a treatment supporter (TS) during the whole or parts of the DOTS treatment had their needs for information, advice and care catered for by the TS. The patients' right to dignity and autonomy was ensured and the patients were open about the disease to friends/community which resulted in positive reactions from friends and community. Few patients who were attending a health clinic on a daily or weekly basis had their needs for information, advice and care catered for. Problems with making sense of the information given, power structures and lack of involvement of family resulted in passivity and poor communication. Lack of openness resulted in judgement and discrimination from friends and community. On a public health level a good relationship and good communication between patients and HWs/TSs indicates that good treatment adherence is more obtainable and that TB detection rates are likely to increase as there is more openness regarding TB and HIV/AIDS in the communities. Better adherence and increased detection rate will help to control TB and slow down the development of drug resistant TB.

Abbreviations

AIDS:	Acquired immunodeficiency syndrome
CHEP:	Copperbelt Health Education Project
DOTS:	Directly observed treatment – short course
FGD:	Focus Group Discussion
HBC:	Home based care
HIV:	Human immunodeficiency virus
HW:	Health worker
LHL:	The Norwegian Heart and Lung Patient Organization
MDR-TB:	Multi drug resistant TB
NGO:	Non-governmental organization
STD:	Sexually transmitted disease
TB:	Tuberculosis
TS:	Treatment supporter
UNDP:	United Nations Development Program
WHO:	World Health Organization
XDR-TB:	Extensively drug resistant TB

Definition of key terms

Adherence: “The extent to which a patient continues the agreed-upon mode of treatment under limited supervision when faced with conflicting demands, as distinguished from compliance or maintenance” (1). The term adherence instead of compliance is often preferred by health professionals as it takes into concern patients’ active participation in treatment (2).

Autonomy: “The quality or state of being self-governing” (3).

Compliance: “The degree of constancy and accuracy with which a patient follows a prescribed regimen, as distinguished from adherence or maintenance” (4).

Dignity: “The right to be treated with respect, including the delivery of services, without stigma, prejudice or discrimination by health-care providers and authorities. The right to high-quality health care in a dignified environment, with moral support from family, friends and the community” (5).

DOTS: ”DOTS, or Directly Observed Treatment- Short course, is the internationally recommended strategy for TB control that has been recognized as a highly efficient and cost-effective strategy. DOTS comprises six components: 1. Pursue high-quality DOTS expansion and enhancement, 2. Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations, 3. Contribute to health system strengthening based on primary health care, 4. Engage all care providers, 5. Empower people with TB, and communities through partnership and 6. Enable and promote research” (6).

Empathy: “The action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having the feelings, thoughts, and experience fully communicated in an objectively explicit manner” (7).

Health Communication: “Interpersonal or mass communication activities which are directed towards improving the health status of individuals” (8).

Humanity: The term humanity describes the quality of being civil, obliging and respectful towards other human beings. Empathy, dignity and autonomy are central in the term humanity, and humanity involves a commitment to maximize benefits obtained by health care as well as a commitment to minimize any harm (9).

HW: A person who has a formal education in providing health services e.g. nurse, nurse-assistant.

Interpersonal communication skills: Skills that establish and develop mutual understanding, trust, and cooperation. “Considers and responds appropriately to the needs, feelings, and capabilities of different people in different situations; is tactful, compassionate and sensitive, and treats others with respect” (10).

TB: “Tuberculosis, or TB, is an infectious bacterial disease caused by *Mycobacterium tuberculosis*, which most commonly affects the lungs. It is transmitted from person to person via droplets from the throat and lungs of people with the active respiratory disease. The symptoms of active TB of the lung are coughing, sometimes with sputum or blood, chest pains, weakness, weight loss, fever and night sweats. Tuberculosis is treatable with a six to eight months course of antibiotics” (11).

Traditional healer: A person who is practicing traditional medicine, which is defined as “the health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being” (12).

TS: In the DOTS treatment program a TS is often a former TB patient, a family member or a neighbor who has been trained to assist and observe the TB patient in the daily treatment program.

1. Introduction

TB is a major public health problem in the world today, although effective drugs have been available for this curable disease for many years. The disease is lethal without proper treatment. Patients who have been infected and sick with TB have to go through an eight months long and difficult treatment that is referred to as DOTS. TB is closely linked to poverty as people with already weakened immune systems due to malnourishment and poor access to health are more vulnerable to TB. The break out of the HIV/AIDS pandemic in the 1980's led to a resurgence of TB, and the co-infection of TB-HIV is a major cause of death among patients with HIV/AIDS (13).

The long treatment regime that TB patients have to undergo is challenging to both the HW and the patients and their families, and treatment adherence has for many years been recognized as a challenge. The success rate of TB treatment increased significantly after the introduction of the DOTS strategy compared to what the treatment success was when people were treating themselves without the close follow-up of a DOTS program (14;15). However, many treatment programs and strategies, among them the DOTS strategy, have been developed on basis of what health professionals consider to be the best treatment for the patients, and the DOTS strategy has been criticised for not taking the patients rights to autonomy enough into consideration. Several factors have been identified as barriers to treatment adherence: e.g. organisation of treatment and care; interpretations of illness and wellness; the financial burden of treatment; knowledge, attitudes, and beliefs about treatment; law and immigration; personal characteristics and adherence behaviour; side effects; and family, community, and household support (16).

Research has shown that there is a strong correlation between poor communication in the patient-HW/TS relationship in the DOTS program and poor treatment adherence. HWs and TSs have in several studies been reported to be poor communicators who communicate without empathy and involvement. They have in addition been criticised for making assumptions on what is the best treatment for the patients. Research has, however, not been specific when describing what patients experience as poor communication and what the term poor communication signify. This study is therefore important in order to bring more knowledge into this field (16-21).

Many countries, among them Zambia, have put effort into strengthening their DOTS programs e.g. by involving communities in order to improve treatment adherence and increase case detection rate, by establishing cooperation with traditional healers to prevent delay in detection and treatment, and by strengthening the interpersonal communication skills of HWs and TSs (22;23). Treatment adherence has improved in Zambia the recent years due to efforts to strengthen the DOTS programs, and the treatment success rate increased from 75% in 2001 to 84% in 2005 (24). The TB detection rate is, however, only at 53%, far below the global target of 70% (24;25). Little research has been done to explore the correlation between low detection rate and communication in DOTS programs.

The main objective of this study has been to explore how TB patients experience participating in a DOTS program by exploring how patients seek and receive information and advice and how they seek and receive care in the DOTS program. The findings in this study will contribute to reducing the knowledge gap that exists regarding TB patients' perceptions of good and poor communication, and regarding how good and poor communication influence the patients.

This qualitative study was conducted in Zambia. Zambia is a developing country that is heavily burdened with TB and HIV/AIDS. The Zambian organization CHEP has implemented program activities, in cooperation with the Norwegian organization LHL, aimed at strengthening the communication skills of HWs and TSs who are working in DOTS programs in the Copperbelt province of Zambia. The DOTS treatment programs in Zambia require that patients are frequently in contact with a HW or a TS. The CHEP activities were implemented as an effort to improve the treatment adherence among TB patients and to ensure that TB patients are treated with respect and dignity (22). The CHEP activities were implemented on basis of feedback from HWs and TSs who emphasised that there was a need for communication skills training. The study was initiated in order to explore how TB patients experienced the communication in a DOTS program.

This paper will through the background chapter give the reader an introduction into the worldwide burden of TB, the DOTS strategy and Zambia. The literature review will give the reader insights into knowledge gaps and why this study is important. The methodology chapter will further give a thorough explanation of how this project was executed. The findings of the study will be presented in a descriptive manner, and finally the findings will

be summarized and discussed with reference to relevant literature in the discussion chapter at the end of this paper. The public health implications of this study will also be discussed in the discussions chapter.

1.1 Background for research

TB does, in addition to having an individual impact on the lives of those that are sick with TB and their families, have serious public health implications. In order to see TB in a broader public health perspective some background information on TB, the DOTS strategy and some facts about Zambia will be presented.

1.1.1 Worldwide burden of TB

In 2006, 9.2 million new cases of TB were detected worldwide and 1.7 million people died of TB. South and East Asia and sub-Saharan Africa are today the areas that are hardest hit by TB. Of all regions in the world “the African Region has the highest TB incidence rate per capita (363 per 100 000 population)” (26). Both children and adults can get infected and sick with TB. However, most people get sick with TB in their most productive ages from approximately 15-49 years. More males than females get sick with TB worldwide (27). When a patient has been on treatment a couple of weeks the TB bacteria becomes dormant and the patient can no longer infect other people with TB. Adherence to treatment is, however, crucial in order to succeed in treatment and in order not to make the TB bacteria active again (11).

The lethal combination of HIV/AIDS and TB has led to a resurgence of TB, and TB is a major cause of death among patients with HIV/AIDS. Globally there is also a great concern regarding TB due to an increase in the development of new TB-strains that are resistant to drugs used to treat common TB. The increase in MDR-TB and XDR-TB is directly linked to poor adherence to DOTS. In order to meet the increased challenges of TB, TB/HIV co-infection, MDR-TB and XDR-TB, WHO did in 2006 launch “The Stop TB Strategy”. The main component of “The Stop TB Strategy” is DOTS (14).

As a result of the global burden of TB, a target of reducing the incidence of TB was included in the Millennium Development Goals (MDG) from year 2000. MDG Goal 6, target 3 states: “Have haltered by 2015 and begun to reverse the incidence of malaria and other diseases” (15). TB is included as one of the “other diseases” referred to in MDG Goal 6, target 3. The Stop TB Partnership has endorsed the targets, linked to the Millennium Development Goals, to diagnose at least 70% of people with TB under the DOTS strategy, and cure at least 85% of these, by 2005. These targets were set by the World Health Assembly of WHO (25).

In the 2008-MDG report it is stated that halving the TB prevalence rate by 2015 is unlikely, and that the African region is least likely to achieve the goals by 2015. The report further states that “DOTS has not yet made the impact worldwide that it needs if we are to reach the MDGs” (15).

1.1.2 TB in Zambia

HIV/AIDS and TB constitute a large part of the clinical picture in Zambia. About 17% of the population between 15-49 years is infected with HIV. In 2006 the estimated prevalence of TB was 568/100 000 population and Zambia is, as one of the sub-Sahara African countries, one of the countries with the highest prevalence of TB in the world. The average prevalence in the African region in 2005 was 511/100000. In comparison the average prevalence in Europe in 2005 was 60/100000 (11). It was in 2006 also estimated that 37% of new TB cases in Zambia were infected with HIV (13, 14). Not all TB cases are however tested for HIV, so it is difficult to estimate exactly how many of the TB cases that are infected with HIV (22;28). In 2005 WHO indicated that the HIV prevalence among adults who live with TB in Zambia was 62 % (29). Between 1960 and 1980 the prevalence of TB in Zambia was constant at around 100/100 000 people. After the emerging of the HIV/AIDS infection in the mid 80's, the TB prevalence increased to around 500/100 000 population (28).

Tuberculosis in Zambia

553: Estimated Incidence (all new cases per 100,000 population) (2006)

568: Estimated Prevalence (per 100,000 population, incl HIV-positive) (2006)

102: TB mortality (per 100,000, population, incl HIV-positive) (2006)

37%: HIV prevalence in incident TB cases (2006)

100%: DOTS population coverage (2006)

53%: DOTS detection rate (new ss+) (2006)

84%: DOTS treatment success (new ss+) (2005)

(30;31)

As we can see from this table there is an approximate 84% DOTS treatment success rate in Zambia. This means that 16% of the patients are not completing treatment. The WHO goal for DOTS treatment success is 85% (25). Zambia is close to the goal of 85%, however, constant efforts to maintain the treatment success rate is needed. Poor treatment adherence is the main reason for not achieving a higher treatment success rate. In addition it is crucial to notice the low TB detection rate at only 53%. The low detection rate illustrates the great importance of strengthening the DOTS program related to both treatment adherence and case detection.

1.1.3 The DOTS strategy

DOTS can be seen as the core element of WHO's Stop TB Strategy. The vision of the Stop TB Strategy is to have a world free of TB (6;14). The main goal is "to dramatically reduce the global burden of TB by 2015 in line with the Millennium Development Goals and the Stop TB Partnership targets"(6). The Stop TB Partnership comprises a network of international organizations, countries, donors from the public and private sectors, governmental and nongovernmental organizations and individuals who have expressed an interest in working together to achieve this goal of a world free of TB. WHO is the leading partner in the partnership (32).

DOTS originally consisted of five components, but in 2006 one extra component was added to the strategy. The DOTS strategy is revised continuously. It now consists of the following components: 1. Pursue high-quality DOTS expansion and enhancement, 2. Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations, 3. Contribute to health system strengthening based on primary health care, 4. Engage all care providers, 5. Empower people

with TB, and communities through partnership and 6. Enable and promote research (6). Each of the six components comprise several areas that need improvement in order to strengthen the DOTS program (6).

International Standards for Tuberculosis Care (ISTC) and The Patients' Charter for Tuberculosis Care are implemented in the DOTS strategy. “The purpose of the International Standards for Tuberculosis Care (ISTC), developed by the Tuberculosis Coalition for Technical Assistance (TBCTA), is to describe a widely accepted level of care that all practitioners, public and private, should seek to achieve in managing patients who have, or are suspected of having, tuberculosis” (33).

WHO's DOTS strategy has been successful in curing millions of people from TB. Nevertheless, it is discussed among experts in this area whether the acronym DOTS is helpful or not. Many agree that the acronym DOTS is misleading, “because direct observation of treatment (DOT) is the most controversial and least proven component of the WHO-DOTS strategy” (34). The notion that all patients have to be observed every day whilst taking their medicines is suggesting that TB patients can't be trusted to be in charge of their own treatment, and that they are a danger to society. The directly observing component is only one of many components, and some therefore argue that the name “Directly observed treatment – Short course” is misleading. It is important to find out how to provide support within different communities and cultures. Health workers need to create tailor-made, local tuberculosis treatment programs and support strategies based on the patients needs in order to promote treatment adherence. WHO has opened for approaches within DOTS that are more patient-centred and involves e.g. community based DOTS or home based care where a family member or a community member can be trained to support and observe the patient during the treatment, however, many DOTS treatment programs are still rigid and have not opened up for new approaches to make the DOTS treatment more patient-centred (16;34).

The DOTS strategy suggests a standardized treatment with a combination of different drugs. The development of different TB-strains due to e.g. treatment default and interruption of treatment has led to TB-strains that are resistant to the first-line drugs. Other high quality drugs are available for TB-strains that are resistant to the first line drugs. However, WHO is, with good reasons, concerned about the rapid development and spread of MDR-TB. The DOTS strategy emphasises the importance of treatment adherence, reducing treatment

defaulting and interruption of treatment, and ensuring early case detection as a part of the fight against TB and MDR-TB (6;35).

One of the components of the DOTS strategy is “to empower people with TB, and communities with partnership” (6). This component comprises the following tasks: “pursue advocacy, communication and social mobilization, foster community participation in TB care and promote use of the Patients' Charter for Tuberculosis Care” (5;6). This component of the DOTS strategy is central in this research project. In order to continuously strengthen the DOTS program, it is important to empower the TB patients by hearing their voices and exploring their views and opinions on how it is to be part of a DOTS program.

1.1.4 Country profile Zambia

Zambia is located in Southern Africa. It is a landlocked country that borders to the Democratic Republic of Congo, Tanzania, Malawi, Mozambique, Botswana, Zimbabwe, Namibia and Angola. There are nine provinces in Zambia that again are divided into 72 districts (28;36;37).

The population in Zambia was about 11, 5 million in 2004. About 35 % of the population lives in urban areas. There are over 70 different ethnic groups in Zambia. English is the official language, although many people only speak a local language. There are 7 language groups, which again are divided into many dialects. About 69% of the adult population is said to be literate. Illiteracy is more common in rural areas than in urban areas (38). The majority of the people are Christian, and there are smaller groups of Muslims and Hindus (28;36;37).

Zambia is a developing country. Unemployment is a serious problem. Zambia depends on copper for most of its foreign earnings so the economy suffers when copper prices decline (30). UN reported in 2005 that about 64% of the population lived below the poverty line of 1, 25 USD per day. It is in the same report estimated that about 49% of the population were undernourished (37;39).



(40)

1.1.5 Health system in Zambia

Health care in Zambia is provided by various sources. The main health care provider is the government institutions. Additionally care is provided by mining companies, religious organizations, private clinics and traditional healers. Government run facilities are divided into health posts that are the smallest units, health centres, level one hospitals, level two hospitals and level three hospitals (40).

DOTS treatment is provided by several of the above mentioned health care providers, although the government institutions are the main providers of DOTS. DOTS is mainly provided at governmental health clinics. Hospitals are in some cases taking part in the diagnosis of TB by analysing sputum and taking x-rays. Some of the health clinics are now equipped to analyse sputum. Difficult cases of TB like e.g. MDR-TB are referred to hospital level (28).

Although Zambia has a national HIV/AIDS/STD/TB Policy they have not succeeded in combining TB and HIV health services. There is ongoing work to coordinate TB diagnosis and treatment with HIV testing and counselling due to the high co-infection rate. But for now these two treatment programs are working separate in most areas of Zambia. Governmental health institutions are following the WHO recommended DOTS treatment regime (28;41). The governmental health clinics have limited resources. There is a lack of equipment and

medical doctors, and there is a heavy work load on HWs and TSs due to a high number of TB patients. The DOTS treatment provided by government intuitions in Zambia is free of charge.

1.1.6 LHL and CHEP program activities

CHEP, in co-operation with LHL as a technical and financial partner, has since 2004 been implementing programs aimed at strengthening community response to TB and the co-infection of TB and HIV in the Copperbelt province. The development of the DOTS program in areas where CHEP provides assistance is leading to education of community members, often former TB patients, as treatment supporters who can assist TB patients whilst in treatment. The DOTS program has successfully promoted community participation. It is however mentioned that the involvement of the patients families have been limited (22).

In 2007 a three year program on health communication was initiated by LHL together with CHEP in Zambia. The program was directed at developing a communication process training that empowered TB patients by providing HWs and TSs with better communication skills. LHL conducted training programs on health communication in other countries, e.g. Namibia, Tanzania and Lithuania, before initiating the communication skills trainings for HWs and TSs with CHEP in Zambia.

Health professionals have learned about communication in theory, however, communication in practice is a different matter. LHL and CHEP did in 2007/2008 conduct an assessment among HWs and TSs who were working in governmental health clinics with TB patients in the Copperbelt province. The HWs and TSs themselves expressed a need for communication skills training. A communication skills training course for HWs/TSs in the Copperbelt province, called “Health Communication and Management of Emotions”, was in 2008 carried out by LHL/CHEP.

In all LHL activities the TB patients’ right to access diagnosis, treatment, care and support is essential, and the Patients Charter for Tuberculosis Care is an important document in this work. The Patient Charter is stating TB patients’ rights: the right to care, dignity, information, choice, confidence, justice, organization and security (5). Development of the

study objectives and the interview guide in this study is inspired by the Patients Charter for Tuberculosis Care.

1.2 Study rationale

TB is a serious public health problem in the world today. The DOTS strategy is enhanced and strengthened in order to get closer to the goal of a “World free of TB”. New challenges are, however, emerging as TB and MDR-TB is increasing worldwide, despite strong efforts to reduce the spread of TB. Several research projects and WHO global TB surveillance systems can confirm that adherence to DOTS treatment is a challenge (16;21;42). Although WHO has revised the DOTS strategy and are now promoting a more patient-centred approach by providing e.g. HBC, many DOTS providers hesitate to re-organize their DOTS programs (16;21). Several factors are identified as barriers to treatment adherence, and poor communication between TB patients and HWs due to poor communication skills and attitudes among HWs is identified as one of the barriers (16-21). Good communication has been described as important in order to increase treatment adherence and in order to increase the patients understanding of his/her illness and the treatment (43).

Few studies have explored how patients experience the communication with HWs and TSs and how good or poor communication influences the patients (16;21;44;45). It is now important that the patients’ voices are heard, and that their experiences from participating in a DOTS program is assessed in order to increase knowledge about what areas of communication between patients and HWs/TSs need to be strengthened. This study wishes to explore how TB patients experience participating in a DOTS program in order to increase knowledge on how communication influences the patients. How the patient’s needs for information, advice and care are catered for by HWs and TSs will be in focus.

In Zambia the organization CHEP, in co-operation with LHL, has implemented programs aimed at strengthening the communication skills of HWs and TSs in the Copperbelt province as a part of strengthening the DOTS program in the fight against TB. The CHEP implemented programs in Zambia are based on LHL’s previous work on health communication in other developing countries, and on the basis of feedback from HWs and TSs working in governmental health clinics in the Copperbelt province of Zambia. The HWs

and TSs themselves reported that communication with TB patients can be challenging and that there was a need for communication skills training among the HWs and the TSs.

The findings in this study will provide information that can be valuable for the communication skills' training CHEP, in co-operation with LHL, is conducting for HWs and TSs. By bringing the patients' experiences in focus, the training will be more directed towards patients' needs. The findings can provide valuable inputs for further development of LHL and CHEP's work on communication.

1.3 Objectives

Demarcation: This study focuses on TB patients' experiences of participating in a DOTS program. Emphasis will be put on how patients seek and receive information, advice and care, and how they participate in decision making regarding their own treatment regime. These aspects were chosen as they are central in the Patients' Charter for Tuberculosis Care. The aspects of information, advice, care and decision making will be seen in relation to how communication influences the patients. It is acknowledged that other factors might affect the communication, however, these will not be specifically addressed in this study. The study will not assess or explore the direct interpersonal communication between TB patient and HW/TS in a clinical consultation. The study will, however, describe how patients experience the interpersonal communication with HWs and TSs, as well as how patients experience communication with family and friends.

1.3.1 General objective

To increase knowledge on how TB patients experience participating in a DOTS program in order to better understand how communication in a DOTS program influence the patients.

1.3.2 Specific objectives

- To explore what TB patients consider to be the main challenges in life during the DOTS treatment

- To explore how TB patients seek and receive information and advice in the DOTS program
- To explore how TB patients seek and receive care in the DOTS program
- To explore how TB patients are participating in the decision making process regarding their own treatment schedule

2. Literature Review

Literature from the field of TB and adherence to TB treatment is reviewed in this chapter. The issue of communication between health professionals and patients in connection to treatment adherence will be in focus. The literature review will provide us with important knowledge about the research topic and identify gaps in literature.

Literature search was done by using the internet search engine PubMed. When relevant articles were found, the reference list in these articles was used to find other relevant studies.

The review articles by Munro et al (2007) and Noyes (2007) are exploring adherence barriers associated with TB. The individual studies that are reviewed in this chapter are chosen as these studies have discussed the issue of communication related to adherence. Several other articles related to TB and adherence exist, but have not been included in this review as they did not specifically address the issue of communication related to adherence.

2.1 Critical review of existing knowledge in the field

Poor adherence to TB treatment in many countries has resulted in several studies focusing on finding out more about barriers associated with treatment adherence. Along the focus on adherence to treatment, the aspect of humanity in care has come more in focus through the DOTS strategy and the Patients' Charter for Tuberculosis Care.

In the search for relevant literature a large number of articles related to TB adherence were identified. Research articles related to communication in health services in general were also identified. The number of research articles that explored the issue of TB adherence and communication together was relatively few. In several of the many articles related to TB adherence it was, however, stated that communication was seen as a barrier to adherence. Research done in developing countries on long term treatment regimes like DOTS treatment showed that poor interpersonal communication skills of health workers were among the barriers to treatment adherence (16-21).

The review articles by Munro et al (2007) and Noyes (2007) are summarizing findings from different qualitative studies on TB adherence. Barriers to adherence have in the different studies been grouped in many themes; poverty, organization and quality of treatment and care, interpretations of illness and wellness, financial burden, knowledge, attitudes and beliefs, side effects of treatment, personal characteristics and behaviour, family, household and community influences, stigma, gender, patient-health worker relationship and health workers communication skills (16;21). The issue of patient-health worker relationship is identified as one of the barriers, however, it not stated exactly what factors in the patient-health worker relationship that are perceived as problematic to the patients and to the HWs.

Both qualitative and quantitative studies have looked closer into the issue of adherence to TB treatment. Many studies identified communication and health workers attitudes as barriers to adherence (16-21).

In a qualitative study done in Vietnam in 1996 (18), using focus group discussions as data collection tool and looking at gender differences and compliance to TB treatment, it is stated that the interaction between health worker and patient is central when it comes to compliance to treatment. It is stated that: “Unfriendly behaviour from health workers leads to patients feeling uncomfortable, threatened, unwelcome and unwilling to return to treatment” (18). This study does however not give any insight into what “unfriendly behaviour” denotes. The article is further stating that improved attitudes from health workers lead to better compliance to treatment, but does not give an insight into how patients perceive “improved attitudes”. The findings in this report provide important knowledge regarding factors that affect adherence to treatment, and it proves the need for further research on communication and attitudes. The report from this study further indicated that one of its weaknesses was the composition of the FGD. Elder people tended to speak most of the time, so the perceptions of the younger patients were to a lesser degree included in the findings. The fact that this study only used FGD as data collection tool limits the credibility of the findings as participants might not have shared their core beliefs and opinions as to not fall out of social norms and acceptance from the other participants. Strengths in this study were that study sites were located in four different areas of Vietnam, and the sample size was large considering this was a qualitative study. 16 FGDs with 8-10 participants in each group was included (18).

Another study performed in Nepal in 2005 (20), had the objective to study the associations between the behaviour of health professionals as reported by patients, the quality of communication, and patient's communication about their disease and non-adherence to DOTS treatment regime. The study was designed as a case-control study using questionnaires with close ended questions as data collection tool. The case group consisted of 50 cases (non-adherent to treatment) and 100 controls (adherent to treatment) Main result in the study were that poor quality in communication between patients and health professional was significantly associated with non-adherence to treatment (20).

The findings in this study support findings from other studies that have identified communication and attitudes in the patient-health worker relationship as barriers to treatment adherence. The method used in this study makes it possible to quantify to what extent this is a problem in the study area, but it does, however, not give any information regarding how patients perceive poor communication and why this is a problem. The use of questionnaires with closed-ended questions to explore associations of this kind has limitations. How an individual defines quality of communication is depended on e.g. the persons previous experiences and expectations, and the social context. In this study the patients are asked to grade e.g. the health communication with health professionals as: poor, fair or good. Any definition of these terms or explanations on what these terms denote for the patients are not included. Recall bias will potentially be of great concern as all the patients have finished treatment some time back.

A qualitative study in Swaziland in 2005 (19), explored the experiences of people involved in a new community based tuberculosis programme in rural Swaziland. TB patients had their treatment observed by a treatment supporter (either community health worker or family member). The study found that community based care was preferred to hospital care or health clinic care, and that individual and flexible care was influencing the patients' experience of taking part in the DOTS program. The study emphasized the need for improvements of communication skills and attitudes of HWs and TSs, and that it should be recognized that the role of the TSs was not simply to observe patients taking their medicine. The study was using interviews as data collection tool, and it was exploring the experiences of different actors in the community-based treatment program. Purposive sampling was used to identify information rich research participants. The study emphasizes the need for

communication skills training of HWs and TSs, and it is also states that not only the HWs communication skills should be in focus, but also the HWs attitudes.

In a quantitative study in Madagascar in 1993, the objective was to increase the understanding of the determining factors of default in an urban environment where medical facilities were accessible. The results showed that patient information and the quality of communication between patients and health workers were some of the factors related to treatment default. Several TB patients reported that if they for some reason had to interrupt treatment they were afraid to meet the HWs again in fear of sanctions. Several of the participants in this study also reported that they felt that they did not have the opportunity to ask questions to HWs, and that they did not have enough information about the disease and the treatment. The study does, however, not give any insights into why the patients did not ask questions, even if they felt that the information they received was inadequate. The conclusion of this study was that improved communication skills and attention from HWs could encourage more patients to complete the TB treatment (17).

Different research articles (16;21) show that long term treatment regimes put great demands on the patient – health worker relationship and has confirmed that the social relationship between the health care providers and people with TB can be problematic. Beliefs held by some health care providers are stigmatizing, and this can lead to delay in diagnosis and treatment, and it affects treatment adherence as well. Stigma is often associated with gender, poverty and co-infection by HIV (16;21).

The DOTS strategy itself has been criticised for not taking patients' right to autonomy enough into consideration (16). The frequent meetings and dialogue between health worker and patient in a DOTS program put demands on the health worker in order to ensure the patients' rights to care, information, dignity and autonomy (5). This requires that the health workers have good interpersonal communication skills.

The communication between patients and HWs, and the attitudes of HWs have in several studies been identified as problematic. As a response to this more emphasis has been put into developing different communication training programs for health professionals in public and private health services in different countries. The effectiveness of the programs and the

relevance to patients needs in these training programs have however been difficult to prove (45-47). Most treatment programs and strategies have been developed on basis of what the professionals consider to be the best treatment for the patients since few studies have explored the patient's views on what factors are important for them in the patient-health worker relationship (44-48). However, HWs who communicate without empathy and involvement are not necessarily doing this due to bad intentions, but due to lack of awareness and good communication skills they make assumptions on what is best for the patient (45-48).

A study conducted in Lusaka, Zambia in 1999 (49), is emphasising the importance of Home Based Care Programs (HBC) in TB treatment. The aim was to explore the widening role of HBC organisations in the management of patients participating in DOTS treatment. HBC is in Zambia usually organized by NGOs and private organizations that train volunteers who are non-health professionals to be TB care givers. The study states that the strength of the HBC lies in the close contact with the community, including more vulnerable groups as young people and very poor people. The patients in this study reported that the care givers in the HBC were compassionate and caring with the patients, and that they were able to give practical advice. On some occasions it was reported that the care givers had been too forceful. Overall the patients had good experiences with home based care. The study states that the shortcomings of the HBC programs were poor record keeping and failure to meet recommended standards for TB treatment. Another weakness was reported to be limited supervision of care givers by medical staff or coordinators. This study recommends a closer cooperation between the public health system and private NGOs and HBC programs (49).

The importance of humanity in care for patients is clearly stated in the patients' charter for tuberculosis care. It says that patients have the right to: "be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities" (5). Inhumane treatment of patients may lead to complaints, but in settings where the interpersonal relationship between patient and HWs/TSs might not be optimal and the power in the relationship lies with the health professional due to the treatment dependency of the patient, one might not expect to see many complaints due to patients' fear of sanctions that can affect their treatment (9).

A comprehensive qualitative study conducted in Ethiopia in 2003, is exploring the issue of how patients perceive and manage TB symptoms. The study describes that “patients need concrete information about the cause of TB and the rationale behind the long course of treatment to prevent treatment interruption due to misconceptions” (50;51). The study discusses what happens when patients participate in Western, bio-medically oriented programs. Patients use completely different and more traditional explanatory models to what is happening to them than the Western bio-medical explanations. The study points out the importance of the HWs position in this situation. The HWs are often relating to both bio-medical explanatory models and the more traditional explanatory models. This can lead to inconsistency in the information and advice patients receive, and therefore the patients struggle to make sense of both the disease and the treatment. The study also criticizes the health system for being rigid. The importance of creating a good patient-health worker relationship is emphasised. The study further describes how patients are given information by HWs regarding their treatment only once during the whole eight month treatment and that the information given is related to what patients can and cannot do. HWs are not explaining why they can or cannot to certain things. The study emphasises the connection between information, knowledge and empowerment. Empowerment implies that patients are provided with adjusted and relevant information that enables the patients to ask questions in the different stages of the treatment, without being afraid to ask these questions (50;51).

The combination of different explanatory models can create difficulties in the patient-health worker relationship. In the Western bio-medical approaches research has for some time now been exploring what patients consider to be good communication (48). But little is known about what good patient-health worker communication comprise in an African context.

Due to great effort to strengthen the DOTS treatment program in Zambia, by enhancing the community based approach, the adherence to treatment has improved the recent years. (24). The humane aspect in treatment, related to how patients receive care, and the interpersonal relationship between patient-and health worker has however not been much in focus (22).

2.2 Identified gaps in literature

After discussing some of the relevant literature, some areas that need further research have been identified:

- Knowledge about how patients receive care in a DOTS program
- Knowledge about how patient receive information and advice in a DOTS program
- Knowledge about how patients experience participating in a DOTS program
- Knowledge about what a good patient-health worker relationship comprises in an African context
- Knowledge on what patients find problematic in communication with health workers
- Knowledge on what patients consider to be poor communication
- Knowledge on what patients consider to be good communication
- Knowledge on what implications good and poor communication has on patients

2.3 Qualitative vs. quantitative research

Studies related to adherence to TB treatment using quantitative methods like surveys or questionnaires were identified (20;52). These studies give important information regarding the extent of the problem with treatment adherence and showed important correlations between e.g. poor communication and poor treatment adherence. The studies have been efficient in covering a large population, and they are able to generalize findings to some extent. The quantitative studies do however have limitations in being able to contextualize problems and associations. They do not explore why communication is a problem, or how this problem presents itself to the patients. The quantitative studies are important in order to identify areas that need further qualitative research to explore the issues more in depth.

Qualitative research is focused on finding out why a problem or a situation is present. How this problem affects people, and why it affects them. Research is looking for rich data from individuals, and the issue of contextualizing the data collected is essential (53).

Several qualitative studies have addressed the issue of treatment adherence (17-19;48). Due to the complexity of the TB treatment adherence problem some of the qualitative studies appear to be a bit too ambitious for the design of the study, sampling and methods used. This

leaves the reader with some more knowledge regarding the issues in focus, however, some studies do not go deep enough into issues discussed as there are too many issues to be explored. It is, however, often the case in qualitative research that the researcher may only have an idea of what he/she is looking for, and the main issues will be discovered during the research process. This can lead to some studies being overwhelmed with data. It is important to recognize this as a limitation, and it is important that the researcher at this stage is able to be clear about the objective of the study, and that the researcher states in the report what areas are not explored in depth and needs further research.

3. Theoretical background

This study looks at issues related to how patients experience taking part in a DOTS program. How patients seek and receive information, advice and care will be central topics and the underlying theme is communication. It is important to find out who the TB patients are communicating with and how this communication influence the patients. This chapter will provide an introduction to the term “communication”. Most people have a common basic knowledge about what communication is, however, the term communication comprises a number of different associations and meanings for different people (54;55).

3.1 Communication

Communication can briefly be explained as the process of transferring information between a source and one or more receivers. The word communication originates from the Latin word “*communicare*” which means to impart, share, or make common. Communication comprises of an exchange of messages, and when one person is sending a message, the other person is giving feedback, either verbal or non-verbal (54).

Usually the transfer of information is done through spoken or written language, but non-verbal communication plays a significant role in our interactions with other human beings. What we wear, our facial expressions and body language influences the messages we give out. As human beings we constantly communicate information about our feelings, perceptions and intentions, intentionally or unintentionally. “Even saying or doing nothing conveys a message” (54;55).

Communication processes can be very complex; the sender of a message is usually also a receiver of a message, and interpretation of the message will vary from person to person. Communication can depend on a common understanding of what different words, sounds and gestures means in a particular context. This aspect is relevant when discussing communication between patients and health professionals as the different backgrounds and understanding of health can affect the communication between the patient and the health professional (55). There are a number of different theories related to communication. This

section will use Northouse and Northouse (54) and Helman (43) to describe some of the important aspects of health communication.

3.1.1 Health communication

According to Northouse and Northouse (54) health communication is said to have a narrower scope than communication in general. Health communication is concerned with how individuals deal and should deal with health related issues. Health communication again can be divided into interpersonal communication and mass media communication. Interpersonal communication is often seen as one to one communication, or communication in a small group of people. Interpersonal communication requires a two-way communication; that both parties in the communication process are senders and receivers of messages. Mass communication has the goal to reach the wider public in order to send out health messages. Mass communication requires different communications skills and strategies than those required in interpersonal communication. Effective interpersonal communication can be explained as exchanging the right information, to the right people, at the right time. The communication needs to be patient-centred and informative, and promote trust and confidence. The first encounter is important as it forms a basis for all future encounters between the parties in the communication (54). The issues of information, advice and care are factors that are important for the development of interpersonal communication between patients and health professionals. Some important interpersonal communication skills are: awareness, active listening, critical thinking, respect, appreciation, empathy, motivation, responsibility and empowerment. This study focuses on interpersonal communication. When the term communication is used in this paper it refers to interpersonal communication and not mass communication.

The literature review shows that several studies support theoretical descriptions of interpersonal communication, and the both theory and studies have proven the correlation between good and effective communication, and treatment adherence, level of emotional distress and how patients experience the issue of care in the treatment.

3.1.2 Explanatory models

The different background and understanding that patients and health professionals hold is discussed by Helman (43) who is talking about how these differences in background and understanding result in different explanatory models among patients and health professionals. Helman is referring to Kleinman who was the first to introduce the topic of explanatory models. It is stated that “explanatory models offer explanations of sickness and treatment to guide choices among available therapies and therapists and to cast personal and social meaning on the experience of sickness” (43). Patients often hold lay explanatory models that are related to what the common understanding in the community is. These models can result in stigmatizing behaviour since the explanatory model is developed from traditional beliefs that are often based on superstition and fear. The need of “making sense” of what is happening is central for patients. Helman is stating that “the clinician’s diagnosis and treatment must make sense to the patients, in terms of their lay view of ill health, and should acknowledge and respect the patients’ experience of and interpretation of their own condition” (43). Health workers often use explanatory models that are related to biomedical explanations of diseases, and the explanations provided by health professionals do often not make any sense to the patients (43).

The frequent interactions between the patients and the HWs/TSs in a DOTS program can create a relationship that can enhance a shared understanding of the topics discussed. This again can lead to an internalization of the knowledge that is transferred between the patient and the HW or TS (43).

Different explanatory models are dependent on the context they are developed in. A Western bio-medical explanatory model, like e.g. DOTS is based on, will therefore not be easily adapted in an African traditional setting.

3.1.3 Context

The context where the communication is taking place plays an important role as to how the communication develops. The context of the HW-patient relationship can be divided into two important aspects; an internal context and an external context. The internal context refers to who the participants in the interpersonal communication are, and what each of the

parts in the communication process brings to the interaction related to feelings, experiences, needs and expectations. Feelings, needs, previous experiences and expectations of both the parts in the communication are important and will influence the communication. Each participants' desires and values in life, as well as their personality will influence the internal context of interpersonal communication (43).

The external context refers to a large extent to the physical setting in which the communication is actually taking place. It is taking into account e.g. the location of communication, the temperature and noise. The external context is also referring to social influences like e.g. how many people are involved in the interaction and who these people are. Cultural aspects like e.g. religion, social class, economic inequities and gender issues are also a part of the external context (43).

Looking at the communication in this contextual framework will help distinguish between different factors that influence the interpersonal communication process. It can be difficult to fully separate factors in the internal context from the external context as they are closely related to each other.

4. Methodology

4.1 Study design

This study is a qualitative exploratory study.

“An exploratory study is a small scale study of relatively short duration, which is carried out when little is known about a situation or a problem” (56).

Literature shows that there are problems related to the ongoing communication in the patient-health worker relationship, and it is known that it affects patients with regards to treatment adherence. However, little is known about what factors in the communication process actually present themselves as a problem for the patients. I have therefore chosen to conduct an exploratory qualitative study to enrich the understanding of communication in the patient-HW relationship.

4.2 Study site

The study took place in the Copperbelt province of Zambia. This project was initiated in collaboration with LHL and CHEP, and it was therefore chosen to conduct this study in the Copperbelt province, in the areas where CHEP had ongoing program activities on strengthening of HWs and TSs communication skills.

Study participants were recruited from five different public health clinics in the Copperbelt province. This study included participants from rural, semi-urban and urban areas in order to ensure a variation in respondents with regards to treatment regime and experiences from communication with HWs and TSs. Selection of health clinics was done after consulting CHEP staff. The criteria for selection of study sites were that the health clinics were within CHEP working area, and that health clinics from rural, semi-urban as well as urban areas were included. Two urban clinics, two semi-urban clinics and one rural clinic were selected. The selected health clinics were located in Kitwe, Chililabombwe and Lufwanyama districts in the Copperbelt province.

Traditionally the population in a country is separated by whether they are living in urban or rural areas. In this study urban areas are referred to as areas that are densely populated like in a town centre or a city. Rural areas are areas in the country side where settlements are more scattered. In this study we have added the term semi-urban areas. Semi-urban areas in this study refer to areas that are geographically located closer to a town centre or a city than rural areas. The semi-urban areas do, however, have rural characteristics. Many people are farmers, and the density of the population is somewhere in between the high density in urban areas, and the low density in rural areas.

The researcher was based at CHEP's main office in the town of Kitwe which has a population of about 400 000 people.

Permission to carry out the study in the selected sites was obtained from the provincial health director and the district director of health in each of the targeted districts. Ethical clearance from the Ethical Committee at Tropical Diseases Research Centre in Ndola and the regional ethics committee in Norway was obtained.

4.3 Study population

The population targeted in this study was TB patients from the selected public health clinics in the Copperbelt province. The patients in the DOTS programs at the selected public health clinics came from approximately the same socio-economic background that was characterized by low education level and low income. HIV-TB co-infection is a known problem in Zambia, and one can therefore assume that several of the participants in the study were infected and sick with both HIV and TB. Participants from the age of 18 years till 49 years were the target group as this is the age group that are most infected and sick with TB. Study participants with the same socioeconomic background related to education and monthly income were recruited. A denominator for all participants was that they lived in poverty (see chapter 6.2.2).

4.4 Selection of participants

A purposive sampling was used in order to find information rich cases: patients who had personal experiences and perceptions regarding communication with HWs or TSs that they were willing to share (56). TB patients who were on treatment were therefore selected as participants. The selection of patients on treatment was also done in order to minimize the chances of a potential re-call bias that could be present if the participants had finished treatment. Patients in treatment had newly experienced situations that could describe different aspects of the ongoing communication, and they would still remember how the different situations made them feel.

In order to “obtain as complete as possible insight in the issue in all its variations” (56) patients with different ages, and patients who were in different stages of treatment were selected. Participants living in urban, semi-urban or rural areas were selected in order to ensure variation. Both male and female participants were included in the study. It was, however, more difficult to recruit male participants than female participants, as the male participants had to return to their jobs, or they had other chores to attend to after they had collected medicines. Several male patients therefore turned down the request to participate in FGDs, group interviews and individual interviews. The total number of females participating in the study is therefore higher than the number of males participating.

Twelve participants were recruited in urban areas, fourteen in semi-urban areas and eleven in rural areas.

A representative from CHEP assisted the research team in establishing contact with HWs and TSs in the selected clinics in Kitwe, Chililabombwe and Lufwanyama district. A meeting was scheduled for the research team to visit the clinic and to present the project and its purpose for HWs and TSs. The research team did at the same time select a private, quiet and suitable place for conducting interviews and FGD. HWs and TSs further informed TB patients about the project, and patients were asked by the HWs or TSs, in private, if they wanted to participate in the study. The patients who were willing to participate met the research team the next day and were again informed about the project and about their rights as participants in this study (see appendix 3). Patients were given time to reflect on their decision before giving their final answer regarding if they would participate in the study or

not to the research team. The patient information sheet/informed consent sheet was presented to the patients before the individual interview, group interview or FGD started. Most individual interviews, group interviews and FGDs were initiated immediately after the patients met the research team. Some individual interviews were re-scheduled to a time that was more suitable for the patient.

4.5 Sample size

Characteristics	No:
Total number of participants:	37
Gender	
Male	13
Female	24
Age	
18-30	10
31-40	13
41-50	14
Literate	28
Illiterate	9

Individual interviews

A total of 18 individual semi-structured interviews were performed with 15 different TB-patients. Three of the interviews were follow-up interviews. Eleven interviews were performed with male TB-patients, and seven interviews with female TB-patients.

Totally more female TB patients participated in the study, however, more individual interviews were performed with male TB patients than female patients.

Interviews were conducted until we reached a point where the amount of data was sufficient to met the stated objectives and little new knowledge emerged (57).

Details regarding the where the interviews and FGD were performed and how they were executed will be discussed in chapter 4.8.

FGD

One FGD was performed with eight female TB-patients.

Group Interviews

A total of four semi-structured group interviews were performed with a total of fourteen participants.

One group interview was performed with three male TB-patients. Three of the group interviews were performed with respectively five, four and two female TB-patients.

4.6 Inclusion criteria

Patients were selected upon fulfilment of all of the following criteria:

- Diagnosed with TB and had initiated treatment at a local health centre
- Patient was still on treatment for TB
- Part of a DOTS program within LHL/CHEP working area
- Adult, age 18-49 years (adults that could give informed consent on their own)
- Clinically well enough to participate in interview (not bed ridden)
- Patient had been in the DOTS program for at least 1 month (patients had some experience regarding communication with the HWs or TSs)

4.7 Timeframe

Development of research protocol was done from January till June 2008. Ethical clearance from Norway was obtained in August 2008. A provisional ethical clearance to collect data was obtained from Zambia in September 2008. The final ethical clearance to publish data was obtained from Zambia in April 2009. Data was collected during a three month period during the fall 2008 (August till October). Analyzing of data was done from December 2008 till May 2009. Commissioning of master thesis is June 2009.

4.8 Data collection tools

The qualitative data collection methods participant observation, FGD, semi-structured group interview and individual interview were used for data collection in this project. Interview guides and guidelines for FGD were inspired by the appreciative inquiry approach (58). Data collection from multiple data sources is called a methodological triangulation (53;56;57).

The combination of the different methods makes it possible to contextualize the findings and results in an assessment of the phenomenon from different angles. If only one method is used it can be tempting to rely on the initial results. However, if two or more methods are used a critical assessment of the findings is more likely, especially if findings from different methods do not concur (53;56;57).

4.8.1 Observation

Participant observation was in this study used to understand the context of the research, and to be able to put a meaning to what the patients shared in the interviews and the FGD, and to better understand the behaviour of the participants. Participant observation was also used in order to see what people were not able to express with words (59). In the participant observation that was conducted in this study the researcher had a passive role. However, the term participant observation is used since the researcher was present and visible in the setting and the TB patients and HWs and TSs were informed that the researcher was observing them.

In this study the researcher observed the setting where DOTS treatment was taking place. The different health clinics were observed with a view to identify e.g. the physical location, the level of noise, the number of people present and the level of privacy. Some consultations between TB patient and HW/TS were observed from a distance in order to identify the level of privacy in the consultation. This form of observation was also used in order to verify that what the patients were telling in the interviews corresponded with the researchers' interpretation of what was going on in the clinics. The observations were done for the researcher to create an understanding of what was happening and prevent making judgements based on only the statements of the participants. What was said in the consultations between patient and HW/TS was not observed due to language constraints. Informed consent was obtained from all participants before participant observation (56).

4.8.2 Focus group discussions and group interviews

FGD and group interviews were used to gather knowledge about the topics that were most important to the informants related to their experiences of taking part in a DOTS program and their experiences of communication with the HWs and TSs. The FGD intended to stimulate the informants to share ideas and to debate experiences. It did, however, prove to be challenging to get the participants to share ideas and speak freely without guidance and direction from the researcher during the FGD. Four of five planned FGDs therefore progressed as groups interviews instead of FGDs (56). The information gathered in the FGD and the group interviews were a valuable source for shaping the individual interviews. The topics that the patients brought up in the group interviews and FGD as important were included in the interview guide for individual interviews.

Due to the fact that FGDs, and also group interviews, can be limiting in getting to participants' core beliefs and opinions, a higher number of individual interviews were conducted in this study. Some participants tend to agree with the opinion of other participants in order not to stand out from the group, and this was considered when analysing results from group interviews and the FGD. The FGD and the group interviews did, however, provide valuable information in a short time (53;56). Varkevisser et al, 2003 (56) state that participants in FGD should have approximately the same background in order to promote equal participation. In this study it was therefore decided to compose FGD and group interviews with participants of approximately same age (e.g. 20 to 30 yrs, or 30 to 40 yrs.). Participants also had approximately the same socio-economic background in order to promote equal participation. (56) The FGD and group interviews were held in separate female and male groups as this was preferred by the participants.

FGD and group interviews took place in vicinity of the health clinic. One group interview was conducted in an office inside the health clinic. The rest of the FGD and group interviews were conducted outside in open air. Benches and chairs were placed in a private and quiet area so that other patients could not observe or hear what was said in the FGD or group interview. One group interview was conducted in English. In the FGD and three of the group interviews a research assistant translated questions and answers from English to the local language used. The FGD and group interviews lasted for approximately 1 ½ hours. Refreshments were made available for the participants.

The researcher was the moderator of the FGD and all interviews. Research assistant were translating. How translation proceeded will be further discussed in chapter 4.9. The FGD and all interviews were tape recorded after approval from the participants. .

4.8.3 Semi-structured individual interviews

Individual semi-structured interviews were the main source of data collection in this study. Interviews are a way of generating data by having conversations with people. Interviews may vary in form, and in this study we used semi-structured interviews with a prepared list of open ended questions to guide the conversation (57). The literature review and the researcher's background as a nurse played an important role in determining themes and questions for the interview guide. The Patients' Charter for tuberculosis care also influenced the themes that were chosen. The open ended questions were developed on basis of the observations done by the researcher and on results from the FGD and group interviews.

Probing questions that were not pre-defined was used in order to clarify and ensure a deeper understanding of the participants' answers. All participants were asked questions about the same topics, but the formulation of the questions and the sequence of questions varied from interview to interview. The questions were constantly edited in order to make them more specific and contextualized. The interview guide was guiding the conversation and questions, and the questions were also accommodated to how the conversation with the study participant proceeded.

In order not to let the interviewed person be a passive part in the interview, the researcher formulated questions that encouraged the participant to reflect upon the answers (57). The researcher probed questions, and did on-spot validations of answers that were unclear. Care was taken to establish a basic level of trust, and to ensure confidentiality between the researcher and the participant, before discussing emotional and sensitive issues (53;56;57).

The majority of the interviews took place in the vicinity of the health clinic. Some interviews were conducted outside, whilst a few interviews were conducted inside the health clinic in available offices. All interviews were conducted in privacy and in a calm and quiet atmosphere. About half of the interviews were conducted in English. In the other half of the interviews a research assistant translated questions and answers from English to the local

language used. Many study participants did in the beginning of the interviews answer questions with short sentences. The researcher therefore at a later stage in the interview returned to some of the themes that were discussed at the beginning of the interview. When the same themes were brought up at a later stage the participants often altered their answers, and gave more thick descriptions of different situations. The researcher experienced that when questions were abstract and not specific, the participant had difficulties understanding the meaning of the questions. All questions were therefore adapted in order to have the participants elaborate on concrete situations and experiences.

The individual interviews lasted approximately one hour. Refreshments were made available for the participants.

4.8.4 Appreciative inquiry

Appreciative inquiry can be described as a way of creating an understanding of what is working well in the communication process between patients and HWs/TSs. Finding out what people have done previously to manage difficult situations in communication with health workers and exploring positive experiences are in focus, instead of only focusing on the problems (58). One positive outcome of appreciative inquiry is that patients can learn from each other by sharing positive experiences (58). These positive experiences will also be valuable to share with HWs and TSs in the communication skills training in order for them to see and understand the communication context from the patient's point of view. Appreciative inquiry was used by asking the participants to share positive experiences from the communication with HWs and TSs.

4.8.5 Other sources of data

LHL and CHEP conducted a five days communication skills training called "Health Communication and Management of Emotions" for HWs and TSs in September 2008. The researcher was an observer in this training course. Informal conversations with HWs and TSs from different parts of CHEP working area were conducted. These informal conversations gave the researcher a more comprehensive understanding of the structure of DOTS treatment in the Copperbelt province of Zambia. Observing the participants in the communication

skills training also gave an insight into what areas of communication with patients that the HWs and TSs found to be challenging.

Informal conversations with CHEP staff also provided valuable data on how the DOTS treatment is organized in public health clinics in the Copperbelt province.

Three individual interviews were conducted with participants in their homes. Seeing the way participants lived, and meeting the families of the participants, provided more information about who the participants in the study were.

An information meeting was held with a local NGO called Third world images project (TWIP). This is a youth organization that is running several activities. Many of the activities were directed towards prevention and sensitization of e.g. HIV/AIDS, TB, malaria and STD's among people up to 30 years in Kitwe town. TWIP also served a role as a patient support group for youth infected with HIV/AIDS and TB. The information meeting with TWIP showed how this group worked in order to reach the target group for sensitization. The information from TWIP showed that there was a great need for patient support groups for TB patients and HIV/AIDS patients as TWIP received many requests from people wishing to participate in their activities.

4.9 Research assistants

CHEP advertised for research assistants outside CHEP on behalf of the researcher. Potential research assistants were interviewed by the researcher for suitability.

The research team consisted of one researcher and three research assistants.

One full time female research assistant, and one male and one female part time assistant were recruited for the data collection period. All three research assistants had higher education, and all had previous experience in translation and use of computers. The full time female research assistant had college education in social sciences, and had previous experience as a HIV/AIDS counselor. The part time female research assistant had previously worked as a TS and were now employed in an NGO working with HIV/AIDS preventing activities. The male research assistant was a pharmacist. All three research assistants had previous experience in conducting individual interviews.

A two days theoretical training was provided to the research assistants before entering field for data-collection. Practical training was done under supervision of the researcher. The training was an ongoing process, and an evaluation was made after each interview and FGD. The researcher supervised the research assistants when they were assisting in data collection and taking notes in interviews and FGD. The research assistants received thorough information and training regarding the purpose of the study, ethical considerations, plan for data collection and plan for data analysis before entering the field for data collection. The research assistants were not CHEP employees.

All the research assistants spoke English and the local language Bemba, which was most frequently used by the participants in the study. One of the part time assistants also spoke the local language Lamba that was spoken by some of the participants in the rural areas. Some of the group interviews and individual interviews were conducted partly in English and partly in the local language used by the participants. In the instances where the participants spoke English the interviews were conducted solely in English. The researcher asked in all interviews and FGD the questions first in English. The research assistant then translated question and answers into the local language and back to English again. In all interviews one research assistant was translating and one assistant was taking interview notes (60). The research assistants transcribed and translated all interviews and FGD that were conducted in the local language into English. The main researcher transcribed all interviews that were conducted in English.

4.10 Pre-testing of Data Collection Tools

The interview guide was pre-tested on three TS that were former TB patients in order to ensure that the questions were understood the right way, and that questions were culturally and socially contextualized. Pre-testing also verified that the questions were directing the participants to respond in the context of the study objectives. The pre-testing was not conducted in any of the study sites. Although the interview guides were pre-tested, a continuous evaluation of the questions in the interview guide was done. The interview guide was guiding the conversation and questions, and the questions were also accommodated to how the conversation with the interviewee proceeded.

Information sheet/Informed consent sheet was also pre-tested on patients to ensure that language used was understandable and that the messages were conveyed in an easy and clear way (56). The Information sheet/Informed consent sheet was available in English, Bemba and Lamba versions.

4.11 Data Management and Analysis

4.11.1 Data management

All interviews and the FGD were recorded on tape. All participants were asked if they had any objections to tape recording before the interview/FGD started. Notes were taken during the interview/FGD by a research assistant. Data from interviews and the FGD were translated, sorted, written out and discussed by the research team as soon as possible after the interview/FGD. The different interviews and the FGD were therefore scheduled with one or two days apart in order for the research team to manage the data collected from one interview/FGD before new data was collected.

Interview notes and tape recordings were coded with a respondent number. No name or address was written on any notes or tape recordings. The different health clinics and districts were also given a number code. Interview notes and tape recordings were kept in a locked cabinet. Informed consent sheets and list of participants were kept secure in a locked cabinet separate from the cabinet with the tape records and interview notes (56). Only the researcher and the research assistants had access to the data collected.

All data and personal information about the study participants like e.g. name and contact information will be deleted when the project period is over.

4.11.2 Data analysis

A pre-analytic process of the data started already during the data collection period. The researcher and the research assistants listened to the tape recordings and looked at the notes as soon as possible after the interviews/FGD in order to discuss responses of the participants, and to see if the researcher and the different research assistants shared the same

understanding of the participants' statements. Editing and development of the interview guide was also a part of a pre-analytic process. When new themes arrived, which were not anticipated by the researcher, it was decided if these new themes were of such relevance that they should be included in the remaining interviews. The personal reflection that occurred during participant observation also became integral in analysis of the data.

In the period following the data collection period, all data material was more systematically analysed. Malterud's modified version of Giorgi's phenomenological method has formed the basis of the systematic approach the researcher has used in the analysis of the data material. (61;62)

The first step in the process was to get an overview and a general sense of all the data material. The transcripts and observation notes were read in relation to each other with the aim of getting an overview. The next step was to identify themes in each of the interviews. The themes were then divided into categories. This process is commonly referred to as coding of data. The coding was done manually, but the software program, WEFT QDA (63) was used to handle and compare several transcripts at a time. The third step was creating meaning units of the different themes and categories identified. The participants' statements were further examined and interpreted before the patients statements were combined into different meaning units to see correlations between them in order to give a more coherent description and analysis of the data.

The analysis of the data was not conducted to confirm whether people's perceptions were accurate or true reflections of the situation they described. The analysis was important to ensure that the findings in the project accurately reflected what the participants told the researcher.

Citations have been used to illustrate certain aspects of communication. The researcher has corrected some grammatical errors' in the patients' statements, and changed a few expressions in order to make the quotes easier to understand. The content of the quotes has, however, not been compromised.

The role of the researcher is important to bear in mind during data collection and the analytical process. The understanding the researcher has of the topic in focus is based on e.g.

the researcher's background and education, and this understanding will affect the analysis of data. The role of the researcher will be further discussed under chapter 4.14 Reflexivity.

4.12 Dissemination of Findings

The results from this research project will be finalized June 2009 and handed in to the University of Oslo as a master thesis.

Findings will be presented to CHEP and LHL. A copy of the final thesis will be given to LHL, CHEP and the health clinics where participants were recruited. A copy of the thesis will also be sent to Directors of Health in the districts: Kitwe, Chililabombwe and Lufwanyama. A copy of the thesis will be sent to the Ethical Committee at the Tropical Diseases Research Centre in Ndola.

The findings will be sought to be published in international medical journals.

4.13 Discussion of methodology

4.13.1 Trustworthiness

Validity and reliability are important issues to address in quantitative as well as qualitative research. There are many different opinions whether the terms validity and reliability are appropriate in qualitative research. The expression trustworthiness is sometimes used instead to explain the issue of validity and reliability in qualitative research. Trustworthiness comprises issues like credibility, transferability, dependability and conformability.

Trustworthiness relates to e.g. the quality of the data, and the whether or not the methods for data collection were appropriate (64-66).

Credibility

A methodological triangulation of the data collection methods increases the credibility of findings. By using several methods for data collection one can discover if there are any distinct contradictions in the findings related to the different methods. One example here is

how the findings from FGD sometimes can be biased as some participants tend to agree with other participants in order not to stand out from the group. By using individual interviews in addition to FGD and group interviews one can discover other perspectives that are not mentioned in FGD or group interviews.

In this study we used three different data collection methods. No contradictions were discovered as the participants' descriptions of taking part in a DOTS program and their description of communication with HWs and TSs in the FGD did concur with the descriptions the participants gave in the individual interviews. The participant observation also confirmed statements from participants in FGD and individual interviews.

It is important to limit the influence of the researcher's and the research assistants' preconceptions in the ongoing adjustments of the data collection tools (57). There was therefore an ongoing discussion and editing of the interview guide by including new themes that emerged in the interviews. This increased the credibility of the study as the views and experiences of the participants were in focus. This was important as the data collection was a dynamic process.

The purpose of the analysis was to ensure credibility by as accurately as possible reflecting what the participants said, rather than confirming whether people's perceptions were accurate or true reflections of the situation they described.

Follow-up interviews and on-spot validation has also increased the credibility of this study.

Variation in the sampling procedure was done to increase the credibility of the study. If purposive sampling used in this study had resulted in respondents with the same characteristics, e.g. same age or same gender, the credibility of the study would have been in jeopardy since the scope of the study is to collect experiences from TB patients who have different characteristics.

Transferability

Although the findings in this study first and foremost are valid for the participants in this study there is some level of transferability of the findings. By describing the context of the research setting, the study population and the methods used, and by contextualizing the findings the potential transferability is increased. By describing the context one can find parts

or elements of the research one can assume are valid in other settings with similar context, like e.g. in other developing African countries that has organized the DOTS programs similar to the way they have organized the DOTS programs in Zambia (64-66).

Dependability

Reliability is related to the level of repeatability in quantitative research. In qualitative research it is, however, not possible to accurately measure the same thing twice. The term dependability is related to how the researcher acknowledges that there is a constant movement in the research context. It would be impossible for someone else to repeat this study in the exact same way it has been done this time. However, by the thorough explanations and descriptions of what has been done, why it has been done and by explaining what changes have been made during the research process the dependability is strengthened.

Conformability

It is important to assess the role of the researcher in qualitative research. The preconditions of the researcher will influence the whole research process and will affect the objectivity of the study. The methods used and the themes the researcher has chosen to explore, and the analysis of data is greatly influenced by whom the researcher is.

The preconditions of the researcher make it difficult – if not impossible - for the researcher to be objective in qualitative research. The term conformability has been used to describe to what degree the findings can be confirmed by others. In this study conformability was increased by double checking the transcripts. After each interview or FGD had been transcribed by a research assistant, the transcript was re-checked by the researcher or by another research assistant, by listening to the recording of the interview and reading the transcript at the same time. This validation of the content of the transcripts can be related to conformability (64-66).

The trends and consistency in the data were also discussed with the research assistants to ensure that that the meaning of the statements from the participants was seen in the appropriate context (64-66).

Preliminary findings were also presented to and discussed with a few HWs and TSs who were not working in any of the study sites in the project, to see if they recognized the situations presented in the findings.

The role of the researcher in this study as a trained nurse, a non-native speaker and a white and “rich” woman in a developing African country will be further discussed in chapter 4.14 Reflexivity.

4.13.2 Strengths of study

The triangulation of data collection tools helped to strengthen the exploratory nature of this study, and increases its credibility.

The observations were an eye-opener to the researcher to understand the context of research. It also made the researcher prepared to be open for new inputs and themes related to the field of communication. This opened for the participants to bring up new themes, and prevented that the researcher was in full control of the directions all interviews and FGD took. The exploratory and dynamic nature of the project also allowed for discovering the need to change study objectives in order to focus on the topics that were of high relevance to the study participants.

It was also a strength for the study to have competent and locally known research assistants who brought valuable insights and inputs to the research. The research assistants participated in discussions regarding the appropriateness of the questions asked, and they participated in the pre-analytical phase. The research assistants spoke the local languages and had grown up in the areas where research took place. This made them able to introduce the researcher to the study sites in a professional and culturally appropriate manner.

The close cooperation with CHEP made the navigation in a foreign country, and the access to different health clinics easy for the researcher. A car and locally known driver was provided by CHEP. CHEP provided important background information about TB and DOTS treatment in Zambia. It was also a strength for the study that the researcher was initially introduced to the HWs and TSs in the different health clinics by CHEP, which is a well-reputed organization and has worked in these areas for many years. This increased the credibility of the researcher.

The researcher's supervisor assisted the researcher in data collection in two early stage interviews. The researcher got important feedback and insights by the supervisor which resulted in improved interviewing skills. Insights from the experienced supervisor also helped in the revision of the interview guide.

The variation in the study participants' characteristics was a strength as TB patients with different characteristics shared their experiences. Despite the differences in e.g. age, gender, married, single, mother, father - certain shared experiences of taking part in a DOTS program and certain shared perceptions of communication with HWs and TSs were recognized.

As an outsider, I provided a potential neutral and safe arena for the patients to discuss what was important to them, without being judged. Patients brought up issues relating to traditional conceptions of TB causes and treatment. Many patients asked questions when given a chance. Most patients responded positively to talking about themselves, and reflecting about their situation, and gradually opened up as the interview progressed.

4.13.3 Weaknesses of study

In a qualitative study of this exploratory nature it is important to acknowledge the constant movement in the process. This movement was experienced in this study by the fact that some changes had to be made to the original plan. The movement and the dynamic nature of a qualitative study is not to be seen as a weakness, however, certain issues emerged in the process that might have affected the final results.

Recruitment process

The recruitment process was done with the help of HWs and TSs at the different health clinics. The fact that it was a HW or TS who initially asked the patients whether or not they wanted to participate in the study might have led to some patients agreeing to participate without actually wanting to do so. Some patients might have felt inferior to the HWs and TSs, and this might have led some patients to say yes to participate. The researcher always gave the participant the opportunity to withdraw when they met the research team. A few patients did at this point choose to not participate in the study after they were ensured that it would not interfere with their treatment at the clinic. After some initial challenges regarding

the recruitment a more thorough explanation about voluntariness was given to the HWs and TSs who assisted in the recruitment.

All patients that are included in this study are participating in the DOTS program and are therefore also adherent to treatment at the point of the interview. This makes it difficult to say something about how good or poor communication can influence the patients' ability to adhere to treatment.

Interviews and FGD conducted at the health clinic

Apart from three interviews, all interviews were performed in or nearby the health clinic. Although privacy was ensured in the interviews and the FGD, the participants might have withheld some information as HWs and TSs were present at the clinic. The decision to conduct the interviews and the FGD at the clinic was made after consulting CHEP staff and the research assistants. A few interviews were conducted in the patients' homes. It was experienced that this created curiosity among neighbours. It was therefore difficult to ensure privacy and a calm atmosphere during the interview. The choice was therefore to conduct the interviews and FGD in the proximity of the health clinic although this choice might have affected some of the answers from the patients.

FGD and group interviews

The FGDs did not proceed as expected. A number of issues could have contributed to the challenges, with language being the most difficult one. The researcher had to direct and guide the participants throughout the whole FGD, and therefore decided to refer to some of the planned FGDs as group interviews. The direct guidance and lack of discussion among the participants may have limited the scope of answers from the participants.

Difference in social class

The research assistants and the researcher were considered to come from a higher social class than the research participants due to a higher level of wealth and education. This skewness in social structure may have led some participants to withhold information in an effort to try to come up with an answer they believed the researcher wanted. This was managed by explaining to the participants that we wanted to hear their story and their true experiences.

The researcher and research assistants also made an effort to dress appropriately and to enter the clinic on foot so as to not demonstrate power.

One of the research assistants in the project also had former experience working as a TS. The research assistant had a tendency to automatically start educating the study participants during the interviews. The research assistant was explained by the researcher that the intention of the interviews was not for her to bring in any sort of education in the interviews, and that possible question the study participants raised should be discussed after the interview was formally ended. The research assistant was explained that her taking the role as a TS or educator could lead the patients to withhold information as the perception of difference in social class and authority could increase.

Language

Language barriers are a weakness of the study. About half of the interviews and FGD were translated by the research assistants. It is inevitable that some information was lost during the translation as the research assistants were not professional translators. Probing, on-spot validation and follow-up interviews were used when it appeared that that information from the participants was lost during translation in order to understand what the patients were referring to. This was important in order to create a shared understanding, and to ensure that the researcher and the study participant were discussing issues related to the same themes.

HIV-TB co-infection

Several patients were co-infected with TB and HIV. Some chose themselves to reveal their HIV status to the researcher. The researcher did not ask the patients to reveal their HIV status as this was not considered relevant for the study in the initial phase. The close link between HIV and TB did however come up as an issue in several interviews. Knowing the HIV status of the participants and bringing HIV in as a central theme might have influenced some of the answers the patients gave. The importance of co-infection for the questions under investigation was not explored further in this study.

Details on socio-economic background

The study participants' monthly income, their marital status and education level were not specified in this study. These issues did, however, come up during the interviews when the

participants talked about themselves. Thus, the information the patients shared in the interviews of being poor and not having access to higher education were considered sufficient “indicators” of poverty, and the researcher, therefore, did not explore these issues any further. It is possible, however, that if these issues had been included in the data analysis other perspectives had emerged in the findings.

4.14 Reflexivity

The researcher’s previous knowledge and understanding

My education and work experience as a nurse in Norway and my previous work experience as a nurse in developing countries like Pakistan and Bangladesh have given me important knowledge regarding working and living in a developing country, it has at the same time provided me with certain expectations towards developing countries. My experience from health communication in both developed and developing countries, as well reading extensive literature about the topic, have provided me with knowledge regarding how good and poor communication can be practiced. This knowledge has guided my choices regarding issues to conduct research on, and it has influenced what I observed. Although I was selective in my observations, I was as a foreigner able to see things from an outsider’s perspective, and this has advantages as well as disadvantages.

Being white and “rich”

The fact that I was a white person coming from a rich country also affected the study participants in the way that some did ask for money from me. In order to keep the participants focused on the interview I learned that it was important to spend some time with the participants telling them about my situation as a student in Norway. Having some time to small-talk before the interviews made both me as a researcher and the participants more comfortable in the situation.

Being humble, open about the research purpose and appreciative for all the help from the HWs and TSs was important in order to create a good and friendly relationship with HWs and TSs who in the beginning seemed to be sceptical to let the research team interview the TB patients.

Being female

I did not experience or perceive my female gender as a hindrance in any situations. All nurses in the health clinics were female. TSs were both male and female. My curiosity and search for new knowledge that the HWs, TSs and patients possessed, resulted as I see it, in a balance in the interviews. I also believe that my gender could be an advantage as female participants felt comfortable opening up in the interviews since I was female. The researcher being white and rich did make the study participants curious.

It was deemed necessary by CHEP to have a male driver to accompany the female researcher and female research assistants in the field. This was seen as important to avoid rude comments and approaches by parts of the male population as I stood out from the general public. I did, however, not feel that the research team in any way was hindered to do its job by being accompanied by a male driver.

Cultural understanding

Since I had never visited Africa or Zambia before, I allocated time in the beginning and throughout the study to gain a cultural understanding. This was done by spending time with local people and by observing how people interacted with each other. Nevertheless, my cultural understanding of Zambia is influenced by me being Norwegian, and this will affect how I have interpreted and presented the findings.

Interview guides were pre-tested to ensure that they were culturally acceptable. However, being a foreigner with a different cultural knowledge might have led me to ask questions that e.g. a local HW could not have asked. It appeared that the participants allowed me as a foreigner to ask questions that were considered to be very direct. I did not experience that people hesitated or refused to answer.

Credibility as a researcher

In order to gain credibility and trust among the participants it was important that I as a researcher showed the participants that I respected their culture and made a truthful effort to understand their position. By e.g. showing respect and appreciating their contribution to the study, by being on time, by dressing appropriately, by bringing research assistant who spoke

their language, by telling the participants about myself, by being honest and explaining my role I gained trust and credibility among the participants.

The few interviews conducted in the homes of the participants did enable me to better contextualize the responses from the participants. It increased the credibility of me as a researcher when I could explain to the participants that I had visited and seen the areas they lived in.

5. ETHICAL CONSIDERATIONS

This study was conducted according to ethical standards stated in World Medical Associations “Declaration of Helsinki” (67) and the CIOMS International Ethical Guidelines for Biomedical Research (68).

The research project was approved by the Regional Ethical Committee in Norway and the Tropical Diseases Research Centre (TDRC) Ethics Review Committee in Zambia before implementation. The research project was also approved for implementation by the Norwegian Social Science Data Services.

Special attention was addressed to ensure the issue of confidentiality and anonymity of research participants (69).

Informed consent, confidentiality and anonymity

A voluntary informed consent from all research participants was obtained, and all participants were in the local language and in an understandable way informed about the purpose of the study, what the information would be used for, who would have access to the information, why it was important, what the benefits were, what the risks were, and where findings would be presented. Only patients that were fully able to give their own informed consent were included in the study. Patients had the possibility to ask questions before deciding whether to participate in the study or not. Patients were informed that they could withdraw from the study at any time without giving any reason for this. They were also informed that not participating would have no consequences for their medical treatment or for their access to, or quality of health services. This study was non-experimental and non-clinical in nature. The study did not interfere with the treatment regime of patients.

Patients were informed that all information would be treated confidentially, that no citations or direct descriptions of situations would be used without their consent. They were informed that anonymity would be ensured by keeping personal information like name and address in confidence, and that no name or address would be used in connection to any data collected. They were also informed that all data collected would be used for the purpose of this study only. All data collected was protected by the main researcher and kept in locked cabinets.

Lists with names and addresses were not kept together with interview notes or tape records. Only the research team members had access to the data collected.

The use of tape recorder in interviews and FGD was approved by all participants, and participants were informed that they could request the tape recorder to be turned off at any time during the interview/FGD. Participants were informed that the purpose of the tape recorder was so the researcher at a later stage would be able capture and understand the accurate context and meaning of what the participant was saying, and that tape recordings would be used for verification and quality insurance.

The presentation of the findings from the study is presented in a way that ensures confidentiality of research participants. The main researcher was given permission by the participants to use citations and descriptions of situations. No names or addresses are presented in any of the findings. Participants were informed that they could contact CHEP in the end of June 2009 if they want to read the final results of the study.

Benefits, costs and risks

Due to financial vulnerability of the research participants we did not use incentives or monetary support as a motivation to participate in the study. Refreshments were served, and travel costs were reimbursed. We did, however, ensure that reimbursement of travel-costs did not become an unintended financial inducement for participating in the study.

As per international standards a person is considered an adult from the age of 18. In this study we only included adults as participants.

As sensitive issues were discussed in some of the interviews the interviews were scheduled so that one could extend the length of the interview if patients needed more time to express their feelings and thoughts.

The benefits of this study are both individual and societal. The study can contribute to improving the communication between patients and HW/TS in a DOTS program. The benefit for the participants was that they had a possibility to share their thoughts and reflections.

This study was facilitated by CHEP. The study will give additional information to the already ongoing work CHEP and LHL are doing on health communication.

6. Findings

6.1 Introduction

The main objective of this study is to increase knowledge on how TB patients experience participating in a DOTS program in order to better understand how communication influences the patients. Exploring what the patients' main challenges in life are during the DOTS treatment, and how patients seek and receive information, advice and care in the DOTS treatment have been in focus. We also wanted to explore how patients participated in decision making process regarding their own treatment schedule in the DOTS program.

In order to best possibly contextualize, and put a meaning to, what the patients told in the interviews and the FGD it is crucial to have through knowledge about the context of the DOTS program and where communication is taking place. The first section of the findings chapter will therefore introduce the reader to the context of a DOTS program in the selected study sites in Zambia.

The second section of the findings chapter will describe how the participants' experienced living with TB and give answer to what the patients considered being their main challenges in life during the TB treatment.

The third section will look closer into the issues of how patients seek and receive information and advice. Information and advice are central topics in the communication between HWs/TSs and TB patients.

The fourth section will look at how patients seek and receive care in the DOTS program. The issue of care is closely related to what patients perceive as good and poor communication with HWs and TSs.

The fifth section will address the issue of how patients are participating in decision making regarding their own treatment. This issue was reported by several patients as important for them.

The issues of information, advice, care and decision making all influenced the patients' experiences of taking part in a DOTS program and it also influenced the communication between patients and HWs and TSs.

The findings will be presented without further discussions in chapter 6, in order for the reader to clearly differentiate between what the patients told the researcher and the interpretations of the researcher. The findings will be discussed in relation to how good and poor communication influence the patients in chapter 7.

The participants own mode of expression will to a large extent be used to illustrate the situation they are in. The descriptive manner the findings will be presented in will also serve to continuously describe the findings in the context they are happening in.

6.2 Contextual background

This section will introduce the reader to the main characteristics of the DOTS program and the communication setting in the targeted sites of this study. The context will be described by dividing it into an internal and an external context in order to illustrate the complexity in the context (see chapter 3.1.3).

In order to increase knowledge on how the communication process between TB patients and HWs/TSs is taking place during an eight month long DOTS treatment, it is important to explore the communication setting from different angles.

The following description of the context will be based on the researcher's observations, interviews with key informants and interviews with TB patients. The internal and external contexts are closely linked to each other, and it can be difficult to fully separate aspects that are related to internal context from aspects that are related to external context. Some overlapping between the two aspects must therefore be allowed for.

6.2.1 External context

Physical aspects

In this study we visited five different governmental health clinics. One of the five clinics was a clinic dealing exclusively with TB patients. The other four clinics were health clinics handling all aspects of public health like e.g. antenatal care, mother and child care, vaccinations, HIV/AIDS testing and counselling and DOTS treatment.

All clinics were located centrally in the town or area they provided health services for. Several of the patients did however have a long journey (up to six hours) from their home to the clinic. Long travel distances were more common in the rural and semi-urban areas than in the urban areas.

Specific days and times of the day were reserved for patients to come and collect their medicines. Early mornings from 08 am to approximately 10 am were the peak hours for collecting medicines. A table where medicines and registration cards were placed was called the “DOTS corner”. Four to five HWs/TSs were often seated behind this table. The HWs/TSs distributed medicines and consulted the patients from the DOTS corner. The DOTS corner was in some clinics placed outside the health clinic and in some clinics placed inside the clinic in the waiting room area. Offices or separate rooms were not used as a DOTS corner in the clinics visited in this study. Patients were seated on wooden benches or chairs, in front of the DOTS corner. It was common that 10-20 patients were waiting in line to receive medicines. In two of the clinics we visited the DOTS corner was placed next to the maternity care area and vaccination clinic. This resulted in a lot of background noise in the DOTS corner from children crying and people talking.

The first two months of treatment were at all the five clinics we visited called the “intensive phase”, and the last six months of treatment were called the “continuation phase”. How the different clinics organized the intensive phase and the continuation phase varied slightly from clinic to clinic. All clinics had several patients who in the intensive phase came to the clinic every day to collect medicines and to be observed whilst taking the medicine. Other patients in the intensive phase came to the clinic once per week or once every second week to collect medicines. These patients had the responsibility themselves to put a pen mark in their registration card every day they took their medicines. HWs/TSs marked the registration

card if the patients received medicines from the clinic. Some patients could send their relatives to collect medicines for one or two weeks if they brought the patients registration card with them.

Urban and Rural aspects

The encounters between HWs/TSs and patients in a DOTS program depended on e.g. for how long the patient had been on treatment and how the specific health clinic had organized the DOTS program. The inclusion of patients in this study who had been on treatment for a minimum of one month up till eight months gave us a comprehensive picture of how and where the encounters between HWs/TSs and patients happened. All encounters varied according to the specific health clinic, the patient and the HW or TS involved.

There was a clear difference in the use of TSs in the rural and semi-urban clinics, compared to the urban clinics. In the rural and semi-urban clinics the TS played a very central role in the DOTS treatment. In these clinics a DOTS corner nurse supervised the TSs, however, it was mainly the TSs who distributed medicines and consulted the patients. In the rural and semi-urban health clinics we visited it was also a common practice that TSs travelled home to some patients several times during the DOTS treatment. The TSs were based at the health clinic, and tasks were distributed among TSs by HWs or the DOTS corner nurse. TSs were recruited from different areas, and each TS had responsibility for patients who lived in the vicinity of their own home. This reduced travel distance and travel costs for the patients who did not have to travel to the health clinic every day. More frequent visits, up to two till three times per week, were common in the initial phase, but several patients told that also during the continuation phase the TSs visited the patients at home. If a patient was in too poor condition to come to the health clinic, the TS travelled to the patient's house every day in the initial phase to give him/her medicines. Study participants reported that TSs came to their house not only to distribute medicines, but also to consult the patients on their condition and talk to both the patient and the patient's family members about TB.

In the urban clinics the use of TSs was less common. HWs were responsible for distribution of medicines and consultations. Some TSs were connected to the health clinics, but were used mainly to trace patients who did not come to collect their medicines. Visiting patients in their homes was not a common practice.

All the health clinics had limited space. Several patients reported that they had not had their monthly check-up by a doctor, or a clinical officer - a person with three years training in clinical medicine, surgery and community health, which they had been informed about in the beginning of the treatment. In two of the health clinics the HWs and TSs confirmed that few patients had their monthly check-up by a medical doctor or a clinical officer, due to the fact that few medical doctors or clinical officers were available. In case a patient was severely ill he or she was referred to a hospital by the HWs or TSs.

Cultural aspects

The distinction between rich and poor in Zambia has resulted in a hierarchy where a difference in social classes is clear. The majority of participants in this study come from the lower part of the social ladder. Most of the TSs come from the same social class as the study participants.

The HWs are ranked higher in the hierarchy due to their education, and can be considered middle class although they are surviving on a limited salary and are not considered rich by the means of money or material goods.

It is expected that one shows respect for the elderly and those higher in the hierarchy. Women, especially in the lower social classes, have traditionally been caring for the household, whilst the men have been in power of income and money. Nowadays it is however common to see women working e.g. in markets selling vegetables. Efforts to increase women's rights has strengthened the women's position and given them a voice in society, but traditional beliefs is slowing down the empowerment of women in the lower social classes.

It is common practice, especially among people in the lower social classes in Zambia, to use traditional healers when experiencing problems related to physical or mental health. There have been efforts to create collaboration between the traditional healers and the public health system. This has been successful in some areas in Zambia. But in many cases the use of traditional healers is still considered to delay the detection and treatment of TB (23). Many of the participants in this study reported that they had been in contact with a traditional healer in connection with their disease.

All participants in the study were Christians', and the strong belief held by the majority of the participants was displayed by a common openness about their religious practices.

6.2.2 Internal context

Living in poverty

Living in poverty was a denominator for all the participants in the study, and poverty was an underlying cause for many of the patients concerns. It was, however, observed that for many of the patients the nature and gravity of their concerns increased after they got sick with TB. Although age and gender, and whether they came from rural or urban areas, varied among the participants in the study, they all came from approximately the same socio-economic background based on the participants' education level, type of work, family income and living arrangements. Most of the male participants' were daily labourers working in the copper industry or in farming. The majority of the female participants were housewives attending children and taking care of older family members. Two of the female participants were solely responsible for household income and were selling vegetables at the marked. All participants came from low income families.

The majority of the participants in the urban areas lived in what is locally called the "compounds". The number of people living in one compound could vary from small families of three to four people, to extended families housing over 20 people. A compound in the area where this study took place could typically consist of a one story brick house with one room and a kitchen. If more than one family shared a compound the compound could consist of more than one house. The houses and a yard were surrounded with fencing. The quality and size of each compound varied, however, simplicity and modest furnishing characterized the average compound. Housing arrangements in rural areas were of similar standard as of those in urban areas although the houses or compounds were more scattered than in urban areas.

Concerns

The participants in this study described an everyday strive for food, that became even more difficult when they got sick with TB. Some patients were not able to work due to poor physical condition, whilst others were forced by their employer to leave their work due to the fact that they were sick with TB. The fact that several patients had to come to the health

clinic every day to collect medicines also resulted in many patients losing their daily income. Most of the participants told us that poor physical condition and loss of daily income made it difficult to provide enough food for oneself and the family. Not having enough food resulted in a poorer physical condition and delayed the patients' return to employment. This vicious circle was common for many of the patients, although their possibility to break the circle of events differed. Those who had a supporting network of family and friends that helped them with food-supplies during the time they were not able to work and helped them take care of the children, managed to avoid a situation of despair and hopelessness due to lack of income and lack of food. However, several of the patients described a difficult life where they every day worried about their future and how they could manage taking care of themselves and their children.

Diversity

Although there are common denominators among the participants like living in poverty, low education level and low daily income, there are many variations among the participants that are important to recognize. Some of the participants lived together with their extended families, whilst others lived alone. Some of the participants were married and had children, and others were single and had no children. Due to the many variations among the participants, their needs, concerns and values in life also varied. The personality of the participants also varied a lot. Some were outgoing and outspoken, whilst did not elaborate on their concerns and experiences.

The internal context is aiming to shortly describe who the participants in this study are. Who they are also says something about how they can influence the interaction with the HWs/TSs. The interpersonal communication is influenced by the characteristics, values and personality of both the study participants and the HWs/TSs (43).

6.3 Living with TB

Poverty was an underlying cause for many of the patients' concerns. This section will describe what the patient found to be the main challenges and concerns in life related to TB. Increased knowledge regarding what the patients themselves consider being the main concern in life is important in order to understand what the patients' needs are.

6.3.1 Managing life

Most of the interviews were opened by asking the patients about their everyday life and about how it is to live with TB. It seemed to be natural for the majority of the patients to answer questions about how it feels to have TB or how TB has affected their lives, by explaining physical symptoms of the disease and physical side-effects of the medicines like e.g. headache, nausea, swollen legs and chest pain. These answers were further probed by asking the patient how e.g. swollen legs or pain in the chest affected their ability to do daily chores and how it felt for them not to be able to do what they wanted to do. By doing this patients were able to describe the main concerns and challenges in their everyday life that were not related to physical symptoms or side-effects of drugs.

The expression “to manage life” was a commonly used by many of the participants as a way of describing how they were able to handle everyday tasks and to fulfil the roles they had in their daily life. Managing life also referred to taking care of your own health and handling physical side-effects of the drugs. The expression managing life was explained differently by each participant depending on their gender, age and their role e.g. if they were married or not and whether they had children or not. However, what was common was that by having TB the patients were often no longer able to fulfil their roles as e.g. an employee in a company, a mother, a husband, a wife or the family’s breadwinner. Many patients reported that being in poor physical condition affected their ability to manage life. Not being able to manage life was a great concern for the patients. Some patients felt that not being able to fulfil their role like they used to before they got sick was difficult as their family, and sometimes friends, had expectations that they could continue to fulfil their role, and family and friends could not always understand why the patient did not manage to live life like he/she used to before they got sick.

A single mother, 35 years, is illustrating how difficult it was for her to manage life after she got sick with TB. Both her role as a mother and an employee was affected, and her greatest concern was for her children. She worried they would starve if her condition worsened and she could not work.

“Sometimes I feel sad when I’m feeling sick and cannot do any work. What hurts most is that I have to use my body to try and fend for my children, but when the body is not fit enough my children will have to starve.”

The differences in what the patients' concerns were related to how to manage life is illustrated by how a married woman, 27 years, explained about her biggest concern:

“For me it is difficult to manage life, because I can't have sex with my husband (...) they said I shouldn't meet [have sex] with my husband until after treatment.”

For this woman it was difficult to meet the expectations of her husband and at the same time follow the advice given from the HW. Her husband could not understand why they could not have sex. This woman also explained that she was never told by HWs or TSs why she should not have sex. She reported that the life together with her husband was difficult after she got TB. Her husband became frustrated and verbally attacked her when she said they could not have sex. Several other study participants also referred to not knowing how to manage sexual relations when they had TB as a part of not knowing how to manage life.

Managing life comprised different concerns from the patients that were not only related to physical symptoms or medication. Still the majority of the patients responded to questions about how they were managing living with TB or how they were feeling, by explaining about their physical symptoms. Some patients said they had never discussed matters that were not of a physical character with HWs or TSs. When discussing concerns that were not related to physical symptoms or medicines several patients became thoughtful and touched. Some cried when telling about their main concerns in life. Several patients requested a need to learn about how to manage life when they were sick with TB.

The married woman, 27 years, who was told not to have sex with her husband is further explaining what she thinks HWs and TSs should do to help her and other patients:

“Like those who are married, tell them how to live and take care of themselves, as well as those who are single. For example if one partner is sick – talk to them as a couple so that they both understand, because some men can never listen to you when you tell them what you have been advised by the clinic. So it's better for them to hear it from here.”

This woman was crying when explaining about how being advised to not have sex with her husband had made life together with the husband difficult. However, when she later in the interview was explaining how HWs or TSs should give patients advice on how they should

manage life, she was no longer specific about the problem with sexual relations between herself and her husband. Instead, as seen in the quote, she referred to a more general lack of knowledge on how to live and take care of oneself. It was difficult for some of the patients to talk about specific problems. Several of the study participants used general terms like how to manage life or take care of oneself, instead of explaining about the actual concern the patient had in mind. The researcher had to probe the study participant's general statements in order to understand what concerns were actually on the patients mind.

In the interviews there was a pattern in the way the study participants responded with explaining physical problems to questions asked about how they were feeling or how they managed living with TB. After they had told about their physical condition several patients asked the researcher if this was the answer the researcher wanted from the patient. Some of these patients explained that when the HW or TS asked them a question, it was about physical matters like e.g. what they were eating and whether or not they had experienced any side-effect from the drugs. The study participants further explained that this was leading them to believe that they could not ask HWs or TSs questions or discuss matters that were not directly related to their physical condition or medication. Parts of this pattern was transferred to the interview setting, however, after the first introduction part in the interviews and when the researcher requested the participants to tell more about their feelings and concerns that were not related to medicines, the patients opened up and told about their difficulties related to managing life.

Although the patients were not used to talking about difficulties in managing life, the majority of the patients gave the researcher the feedback that they appreciated the openness in the interviews in the sense that they could ask the researcher any questions they wanted. The participants usually asked questions in the end of the interviews. The participants expressed a need and a willingness to discuss matters that were not related to physical symptoms or side-effect of drugs. Several patients expressed a desire for a forum where they could discuss all their concerns related to how to manage life and take care of themselves and their families.

The actual need for patients to learn more about how to manage life was confirmed by the many different questions the participants asked in the interviews. The researcher received several different questions regarding: sexual relations (e.g. *why can you not have sex when*

you have TB?), alcohol (e.g. *what happens when you drink alcohol?*), route of transmission (e.g. *can you get TB from sitting here with us? can children get TB?*), relation between TB and HIV (e.g. *if you have TB does that mean you also have HIV?*) and also questions regarding consequences of TB were common (e.g. *when I have finished the treatment, can I have a baby?*)

6.3.2 Knowledge about the disease and treatment

The majority of the study participants had, in addition to having several unanswered questions regarding how to manage life when having TB, an incomplete knowledge regarding TB and the TB treatment regime. The lack of knowledge about TB, the treatment regime and about how to manage life resulted in the patients feeling that they did not master the situation, hence living with TB was perceived as hard and difficult for most of the patients.

The awareness that the majority of the study participants had limited knowledge regarding TB and the treatment regime became apparent during the interviews. When inquiring the participants on what they knew about TB and TB treatment, it was discovered that misconceptions regarding TB and TB treatment was common among the study participants. The type and content of the misconceptions did, however, vary from patient to patient.

Several patients had misconceptions regarding route of transmission. The majority of participants had been told by HWs or TSs that TB was an airborne disease, but many did not understand what airborne disease meant. They knew that TB could infect from one person to another, but it was common to believe that one could contract TB from using the same utensils or from having sex. Several patients believed they got infected with TB since they smoked and drank alcohol several times per week. Believing that TB infected through working with poultry or charcoal, or that TB was heritable were also common misconceptions. Misconceptions regarding transmission of disease became apparent during the interviews when several study participants asked if the members of the research team were not worried they would contract TB from the participants during the interviews. The participants explained that they worried that they could give the disease to members of the research team during the interview. This concern for their fellow human beings was common among the participants.

6.3.3 Reactions from family and friends

Several patients explained how some friends or family members worried that they could get infected by being close to people having TB. And in the same way patients worried that they could infect others. None of the patients had been informed that they could not infect other people after they had been on medication for two weeks.

Several study participants felt discriminated by family, friends or community members when they distanced themselves physically from the patients due to fear of getting infected. The patients expressed feelings of sadness and loneliness due to the fact that people distanced themselves from them.

One male patient, 36 years, is explaining about the different reactions in the community after it became known that he had TB:

“Me, I have experienced that some people can even run away from me, they do not even want to associate with me after getting the information that I have TB, they can not come and chat with me as they think maybe I’ll transmit that disease to them (...) but some other of them they may even encourage you that it is better for you to just be taking the drugs. Then you will be ok. So some attitudes are very different. (...) Me I was told at the hospital that TB is airborne. And you can also get it through drinking beer where we share one container. If someone among us has TB then he can transmit it to the others. I even explain to friends that they can’t be clever where TB is concerned, it can also get to them because it is airborne.”

This participant is calm when telling this story. He explains that he understands the reaction of the people in the community, although he feels discriminated. He is actually making the people around him aware that they can get infected by TB since it is an airborne disease. All the participants in the study knew that TB was a curable disease. However, from what the patients told in the interviews and the FGD it was not well known among community members that TB was curable. This is illustrated in the examples below.

A male patient, 43 years, is explaining:

“Some said they couldn’t greet me in the hand but now they have seen that am looking better, they are saying that sorry we didn’t know that this disease can be

cured. Even today when I was coming here I met one who said: you have changed well, I didn't expect you to be healthy like this now."

This patient is explaining how his friends were ignorant of the fact that TB could be cured.

Another male patient, 39 years, in his last month of treatment, is explaining how his friends reacted after he came back to see them in the final stages of his treatment:

"Right now they are even ashamed because I am fine. They used to isolate me and made me use separate cups and place me in a room which they had abandoned for some time. (...) But when I went to visit them after I was treated they were ashamed to see that I was looking fine."

This patient is explaining that his friends were feeling bad because they used to isolated him. He now believes they feel shameful. The patient explains that he thinks his friends felt that they needed to protect themselves from TB and they were surprised he recovered from the disease.

Most of the patients felt sad when people distanced themselves from them. Although some patients did not blame people around them for being afraid and distancing themselves, some patients experienced people around them being discriminating by blaming the patient for getting sick with TB. One male patient, 48 years, is explaining how his neighbour is blaming him for getting sick with TB because he used to drink beer. The neighbour is telling the patient that the TB-infection is a punishment by God, and that he should be dead now because of all the beer he has been drinking. The same participant is further explaining what the comments from his neighbour made him feel:

"I didn't feel well, I was feeling lonely and sad, especially when I thought about how close we were before I got sick, and how he has abandoned me this time."

This patient, together with several others of the study participants, said that they had friends and neighbours that had discriminated them after they got sick with TB. Many patients reported that when friends and neighbours saw that the patient was loosing weight and was coughing they believed that the patient was infected with HIV. The patients explained that this lead to people sometimes calling them names and shouting at them out in the streets. One patient was explaining that his family first had reacted by isolating him when he told

them he had TB. However, when the patient brought the written test result showing that he was HIV negative from the doctor, the family let him move back into the house. Several patients reported that being discriminated by friends and community members made them reluctant to talk about the disease to anyone and they preferred to not disclose their TB status to friends and community members.

The issue of HIV/TB co-infection came up when discussing with patients how they experienced that family, friends and community viewed a person that was sick with TB. About half of the study participants in this study revealed on their own initiative their HIV status to the research team. In the other half of the group there were some patients that did not wish to discuss the issue, and some said that they did not know their HIV status. A few patients said they did not know what HIV was. Among some of the participants there was a clear confusion about the difference between HIV and TB. That there was a link between HIV and TB was, however, known among the majority of the participants. Since TB is a curable disease, many of the participants explained that were not afraid of revealing to others that they had TB. Revealing one's HIV status was, however, a more sensitive issue. A male patient, 36 years, is explaining:

“I have the other disease which I can reveal secretly, but with TB it was like a simple disease to me so I was not feeling very bad because I knew that TB can be cured.”

In one of the FGD we experienced a female participant that stated loud and clear early in the discussion that *“I only have TB”*. This lady explained that she felt it was important that everybody knew that she only had TB – because this was a curable disease. She did not want people to think that she had HIV. A few other patients in group interviews and individual interviews also stated that they *“only had TB”*. The issue of HIV came up in many interviews, and it was interesting to see how some patients forwarded the message about them not being HIV positive by the statement *“I only have TB”*.

Only a few patients reported that family members had distanced themselves physically from the patients and had been treating the patients badly by isolating them blaming them for getting TB due to their lifestyle of e.g. drinking beer or smoking. Discrimination was reported to be done mainly by friends and community members. The majority of the patients explained in the interviews that their family members accepted that they had TB. What the term *“accepted”* meant to the different patients will be explained further in chapter 6.5.2.

6.3.4 Summary

Living with TB comprised a number of different concerns for the patients. The main concern brought up by the patients in the interviews was about how they should manage life.

Managing life comprised a number of issues related to e.g. sexual relations, work situation, co-infection of TB/HIV and lack of food. Several patients expressed a need get more information and advice regarding issues that were related to how they should manage life, and not only related to physical symptoms of the disease or side-effects of the drugs. Some patients also expressed that they found it difficult to follow advice given from the HW and at the same time fulfil their chores and roles at home.

Several patients also expressed a deep concern about the possibility that they could infect other people with their disease. Misconceptions regarding route of transmission were widespread among the patients and this resulted in some patients isolating themselves from the community. Many patients also experienced people running away from them and shouting at them, which again lead to feelings of sadness and loneliness among the patients.

We will now relate the knowledge we have regarding the main concerns of the patients to the issue of how patients seek and receive advice. The patients often have daily or weekly encounters with HWs or TSs, however, they still have questions and concerns that have not been dealt with.

6.4 To seek and receive information and advice

In the previous section TB patients expressed a need to learn more about how to manage life. The majority of the TB patients also had incomplete knowledge regarding their disease and the treatment regime. This section will explore how patients seek and receive advice by finding out who they ask questions regarding their concerns, who is giving them information and advice, and what kind of information and advice they get. Whether or not the patients understand the information and if they trust the information they have been given will also be explored.

6.4.1 The role of HWs and TSs

Information given during the 1st consultation

The study participants reported that information regarding the disease and the treatment in the majority of cases was given only during the first consultation; when the patient has just been diagnosed with TB. Most of the patients reported that they did not remember the information given to them during this first consultation. Poor physical condition was by many study participants reported to be the main reason for slip of memory.

A male patient, 29 years, is illustrating how difficult it was for him to remember the beginning of the treatment period:

“The first two months after I discovered that I had TB I was so weak, at that time- if I can remember well, I was not moving by myself, I was just being ridden on a bike, I was just being taken by my grandfather, I didn’t have power to move on my own. (...) It is only that I was so sick, in such away that I even lost memory; there are very few things that I can remember.”

Information given in the beginning of the treatment was seldom repeated later in the treatment according to several of the patients. Patients who brought a family member to the first consultation reported that they had benefited from bringing the family member as the family member had reminded the patient about the information and advice that was given in the first consultation. Those who reported being alone in the first consultation said that they could not recall all the information and advice they had been given. Most of the patients reported that they mainly remembered being instructed not to smoke and not to drink alcohol in the first consultation. These participants could not remember being told why it is important not to smoke and drink.

Consulations at a health clinic vs. consultations in the patient’s home

In the encounters between patients and HWs/TSs following the first consultation, several patients reported differences in how they were attended to by TSs at home compared to how they were attended to by HWs or TSs at the health clinic. The role of the HWs and TSs varied from the different health clinics we visited. TSs had a significantly more active role in the DOTS programs in the rural and semi-urban areas than in the urban areas. Participants

that were visited at home in rural and semi-urban areas by a TS, reported that they had enough time for consultations, they had privacy in consultations, they had a close relationship with the TS and a high level of trust in the TS. The patients also reported that family members got involved in the treatment program and got information from the TS on how to take care of the TB patient.

Several patients in rural and semi-urban areas reported that talking to the TSs encouraged them to continue treatment. The patients explained this by the fact that the TS were previous TB patients who had experienced being ill themselves, hence many of the patients felt the TS understood their worries and concerns. The patients who had a TS visiting them at home reported that they felt encouraged and motivated by this.

A female patient, 47 years, is explaining what the TSs visiting her at home told her:

“They talked about how we can take care of ourselves and encouraged us to continue taking medicines. (...) They explained that if you stop taking medicines and start again, nothing is going to work out for you because the TB germ is activated once you stop. The next time it is back again it will come with a force so strong that the medicine will not work again.”

This patient was further explaining that after she was told by the TS that the “TB germ” would get stronger if she interrupted treatment, she was determined to complete the treatment without missing one day of taking medicines.

Several of the patients who were attended to by a HW or a TS at a health clinic reported that the HWs or TSs usually instructed them to take medicines every day and not smoke, drink alcohol or have sex, however, the patients reported that they seldom were told why it was important to take medicines every day or why they could not smoke, drink alcohol or have sex. A few patients reported that these instructions made them believe that smoking, drinking and having sex were the reason they had TB. The patients explained that they due to this were blaming themselves for having TB.

Several patients further reported that the consultations with the HWs or TSs in the health clinic were of short duration. These patients reported that they only collected their medicines and that they did not talk to the HW or TS about their concerns or worries.

Patients seldom ask HWs or TSs questions

Several patients reported that they only received information and advice regarding TB and the treatment during the first consultation. These patients further reported that when they collected their medicines at the health clinic the HW or TS seldom repeated any information or advice. The majority of the patients did, however, report that HWs and TSs on several occasions had requested the patient to ask if they had any questions. When the researcher asked the patients if they had asked the HWs or TSs any questions, the majority of the participants reported that they seldom asked them any questions.

Several patients reported that lack of privacy in consultations due to many patients in waiting in line to collect medicines, was one of the main reasons why they did not ask questions or talk to the HWs or TSs about their condition or concerns. Several patients further reported that the HWs and TSs looked so busy that they did not want to bother them with their questions.

Another aspect that was mentioned by several patients was the fact that there were often four to five HWs or TSs seated together at the DOTS corner. The patients reported being intimidated by this, and reported that they were afraid of being scolded since they did not remember the information that was given to them during the first consultations. Several patients also reported that they felt embarrassed to discuss private matters in front of all the HWs and TSs, as well as in front of all the patients waiting in line. The patients that called attention to the point that several HWs and TSs were seated together also suggested that a different organization of the HWs and TSs would make it easier for the patients to discuss their concerns and worries. A few patients suggested that one day per week should be set aside for the patients to come and ask questions to the HWs and TSs. A few patients also suggested that the HWs and TSs that were seated at the DOTS corner, and did not give out medicines, should be available in the vicinity of the DOTS corner so the patients could ask them questions in private.

Several patients also reported that not being asked any questions from the HWs or TSs in the health clinic also made them reluctant to ask the HWs or TSs any questions. The study participants believed that the reason the HWs and TSs did not ask them any questions was that they were too busy.

Although several patients who collected their medicines at a health clinic reported that they seldom asked the HWs or TSs any questions there were differences among the patients. Some patients reported that if they had urgent matters they needed advice on they would ask if a HW or TS had time to talk to them in private. What was common among the patients who asked questions, however, was that they rarely discussed intimate matters like e.g. how to relate to sexual relations. It was more common to discuss matters that were related to what kind of food they should eat, physical symptoms of the disease or side-effects of the drugs like e.g. swollen legs.

One male patient, 31 years, is explaining how he is selective in what kind of questions he asks the HW or TS:

“When asking questions I look at the things that are troubling me over TB. I don’t ask any other questions. When asking, I only ask about TB medicines. It has always to be related to TB medicines.”

This patient explained that he had several concerns on his mind, but he felt confined to ask questions only about medicines.

Trusting HWs and TSs

Patients who had experiences with relatives or family members who had suffered from TB and who did not recover from the disease reported that due to these previous experiences they did not trust the HW when they told them that they would recover from the disease.

A male patient, 29 years, is explaining how he did not believe what the HW told him in the beginning of the treatment:

“I asked the HW: am I going to be ok? (...) They [HWs] just kept on insisting that no there is no problem, once you have started this medication you are on the right channel [way] of getting healed. But I had that negative attitude in me: is it true, are they telling me the truth? But as time went on, I started improving, I started recovering, and I think I started feeling a change in myself. Then I started to know that this is why they are HWs, they have studied about all these things. So I came to know that TB is curable.”

The same patient further explained what the HWs did to help him gain trust in them:

“They [HWs] used to show me some of the people who had TB some time back. They could say: even that person there had TB, but here she is. She’s doing her work and she’s now ok. Why; she just took the treatment as we were telling her. By seeing this I was also encouraged that maybe one day even myself I’ll be like those who are cured. (...) I was encouraged.”

This patient gained trust in the HW after they introduced him to other patients that had recovered from TB. He needed to see with his own eyes that someone could be cured.

Several patients reported that they had more trust in the information and advice they got from TSs or other former TB patients who had experienced the disease themselves. Study participants that had consultations with both TSs and HWs reported that they felt more comfortable and safe in consultations with TSs who had the same background as them and had grown up in similar circumstances, than they felt in consultations with HWs.

The majority of the study participants who received medicines and had their consultations at home with a TS, compared to those who consulted HWs or TSs in a clinic, reported that they felt free to ask the TS questions regarding TB and TB treatment, and they had a high degree of trust in the information given to them. The participants reported that they could easily compare their situations to the TS, and that hearing from a former TB patient how their treatment course had proceeded was encouraging and trustworthy information.

6.4.2 The role of family and close friends

Many of the patients reported that since they felt that they could not ask the HWs and TSs questions or discuss private matters, they instead asked family members and friends whom they knew had some knowledge about TB. Several of these patients also reported that they had more trust in the information they got from family and friends since they knew them well and knew that they had experience with TB, than the information and advice they got from HWs or TSs whom they did not know from before.

The strong influence the patients' families and friends had on the patients related to their need for information and advice is illustrated by how a male patient, 30 years, is explaining how he followed advice from his close family although he has been advised differently by the HW:

"I went to the clinic (...) and they said: you have TB. After that I came here to the clinic and they gave me some drugs. After two weeks I felt much better. Then my father advised me to stop medication and said: let's go to the village so that you can try some traditional medicine. Then my family took me somewhere in the village and the witch doctor gave me some traditional medicine. It became serious for me. After not even a month, then I was very sick, very very sick again (...) I explained what happened to one of my brothers, he lives town down, and he said: let's go and talk to the doctors at the health centre, they will understand. This brother had TB himself before."

What happened to this patient is illustrating the great influence the patient's family members have on the patient. Although this patient felt improvement in his condition after two weeks of treatment at the health clinic, the advice from his father to discontinue treatment at the health clinic and seek help from a traditional healer weight higher than instructions from the HW to continue treatment for eight months. The patient had, however, never been explained by the HW why it was important not to interrupt treatment. The patient had to personally experience the severe consequences interrupting treatment had on his condition before he decided to return to the DOTS treatment regime at the health clinic. His decision to return to the DOTS treatment was strongly influenced by his close friend that had suffered from TB before.

The patients' families also proved to be important in order to remind the patients about information they had gotten earlier. One female TB patient, 43 years, is explaining how her children were the ones to give her information and advice about what she should do when she got sick with TB for the second time:

"Don't worry, just follow the instructions that you are given by the doctor, and then you will be fine. If you stop taking the medicine the disease will come back again. If you don't look after yourself very well even us as a family we are going to contract the disease."

The patient is explaining that the first time she had TB the doctor told her how to look after herself and the family. She had immediately told her children what the doctor told her. The patient herself had forgotten this information when she got infected and sick with TB again, but her children remembered what the doctor had told her the last time she had TB.

There were differences among the study participants related to whether or not they asked questions and discussed their concerns with HWs or TSs. What was common for the participants, however, was that they all turned to their family and friends for information and advice when they needed it. Whether or not the information and advice from family and friends were correct information and advice varied.

6.4.3 Other sources of information and advice

Some study participants stated that instead of asking HWs or TSs questions they sometimes consulted available unqualified personnel like e.g. the gardener or caretaker at the health clinic. One male patient is describing that since he collected his medicines very early in the morning it was the caretaker at the clinic who distributed medicines to him and gave him information and advice.

The researcher asked the study participants regarding what kind of information and advice the patients had been given from unqualified personnel. One patient reported being advised not to have sex whilst on treatment. Another patient had been advised to move away from his wife and daughter for the whole 8 month treatment period. The advice and information the patients received from unqualified personnel and friends and family was often inconsistent and sometimes wrong.

Other sources of information were wall-posters with information about TB at the health clinics. In one of the health clinics we visited it was, however, observed that all the wall-posters were in English, although only a few of the patients spoke English. In addition several of the patients were illiterate.

The research team had available some TB-information booklets that were developed by LHL in Tanzania. These booklets were tested out on 5 literate study participants. The feedbacks from the study participants were exclusively positive. The study participants reported that

they had learned a lot from the booklets, and that there was a great need for more information regarding TB and treatment among the patients.

6.4.4 Making sense

During the interviews it became clear that many of the participants had a strong need to find logic explanations to the instructions and advice they had been given by HWs/TSs or by family/friends. Most of the patients reported that HWs or TSs did not give any explanations as to e.g. why they should not smoke or drink, or why they should not have sex.

A male patient, 34 years, was advised that he as a single man should not have sexual relations the first 3 months of DOTS treatment. The patients reported that he had heard from another TB patient that married patients were advised that they could have sex up to one time per week. The patient was explaining that he was not given any reason for why single men should not have sex.

The patient reported that he had tried to understand why he as a single man could not have sex, while a married man could have sex during the first three months of treatment. He said that he believed that the medicines would not work as efficiently if you had sex, and he therefore also believed that he, as a single man who did not have sex, had a better chance of recovering from TB, than a married man who had sex. He was giving his explanation as to why the medicines will not work as efficiently if you have sex:

“In the case of a man - one who is married, he will be using energy [sperm] when he has sex - meaning that he will need more proteins. But the one who is not married will not be using energy [sperm], so therefore he will not need extra energy. By using energy you will need more food and proteins. That is why there is a difference between married men and single men. Because then the one who is married is more at risk of not getting healed since he does not get enough proteins.”

A HW had told the patient that it is important to eat proteins and vegetables whilst on treatment. He therefore believed that having sex could reduce the effect of medicines, as the need for proteins would increase. Since the HWs/TSs did not give him the explanation why he should not have sex, the patient had asked some friends what they believed was the reason

one should not have sex when suffering from TB. One of the friends gave the patient the above mentioned explanations as to why one should not have sex.

6.4.5 Summary

TB patients seek and receive information and advice from several different sources whereof family and friends are the most important sources. TB patients report trusting more in what family and friends tell them, than in what HWs and TSs inform them about. Patients also report having more trust in information and advice given from TSs than from HWs. The fact that TSs are former TB patients, that come from the same background and have grown up in the same circumstances as the patients, is reported as the main reason for trusting TSs more than HWs.

Patients in rural and semi-urban areas who were visited at home by TSs were reporting that they felt free to ask questions and discuss concerns, and felt encouraged and motivated by TSs who explained about TB. Patients who are collecting their medicines from health clinics report that they seldom ask questions or discuss their concerns with HWs or TSs. Lack of privacy is reported to be the main reason for not asking questions. These patients are reporting that they instead seek information and advice mainly from family and friends.

TB patients have a need to understand and “make sense” out of the advice and information that is given to them. Patients report that HWs and TSs at health clinics seldom give any explanations as to why they should follow the instructions that are given to them. The advice and information the patients received from HWs, TSs, family, friends and others were inconsistent and sometimes wrong.

6.5 To seek and receive care

This section will look into how patients seek and receive care in a DOTS program. The previous section illustrated the important role HWs, TSs, and family and friends play related to the way patients seek and receive information and advice in the DOTS program. The patients’ needs related to information and advice were seldom fulfilled. This section will

explore what the patients care needs are, and will find out who is providing care for the patients.

6.5.1 The role of HWs and TSs

Nearly all the participants reported that they had been received nicely at the health clinic when they first came for treatment. The majority of the study participants reported that the HWs and TSs were friendly. Several patients reported that for them being received nicely was being received by someone who said hello to them, and who greeted them without blaming them for having TB, and instead told them that TB was a curable disease. To be reminded to take medicines every day was also perceived as a kind act from the HWs and TSs. Some patients further reported that not to be received nicely was to be yelled at or scolded at by the HW or TS.

When the researcher asked the patients about how a friendly HW or TS welcomed them, they reported that the HW or TS greeted them and then gave them their medicines. The patients reported that the HW or TS did not have to ask them any questions or give them any information in order to be perceived as friendly. HWs/TSs who were giving instructions without explaining why they should follow the instructions were also perceived as friendly.

To have a good heart

In order to explore more in depth what the patients perceived as good communication with HWs and TSs they were requested to tell about experiences they had with a HW or a TS who had treated them very well. Patients used the term “to have a good heart” to describe HWs and TSs who they felt had really cared for them in a good way.

To have a good heart was described by several patients as a person who smiles at the patients, who looks at the patients, who stop to talk to the patients, who ask questions about the health of the patients, who listens to the patient and a person who is not in a hurry. Several patients explained that they could tell that someone had a good heart by the way they approached them and talked to them. Some patients also mentioned the facial expression, meaning that if you meet a person who did not have a good heart you would see it in their facial expression. Smiling HWs and TSs, who were walking in a relaxed and normal tempo,

also expressed good attitudes and friendliness. The non-verbal communication of the HWs and TSs was important for the patients.

A female TB patient, 43 years, is talking about one of the HW at her clinic who she feels has a good heart:

“There’s nothing special about her it’s just the way she talks to us. Even if you don’t want to open up you can open up because she’s so humble. She’s a person who can make you feel free.”

Another female patient, 47 years, is explaining how she feels about the TSs:

“They are always nice to me, and they are always there to explain things to me, and they are very encouraging. Some of them even give examples of themselves saying: I was also like you, but look at me am fine now, so you will also be fine. That’s how I could tell that these people are nice.”

A female patient, 30 years, is describing how she perceives a person that does not have a good heart:

“There are some people who talk rudely. For example when you ask them something they just say: I don’t know, go and ask someone else. So I don’t feel good when am being treated like that.”

Not being greeted when arriving at the clinic, not being looked at by the HWs or TSs and being scolded or yelled at or refused treatment was perceived as bad treatment from HW and TS.

The majority of the patients reported being received nicely at the health clinic. Not all study participants could, however, describe a HW or a TS that had treated them really nicely. Several of the patients who reported that they seldom asked questions or discussed their concerns with HWs or TSs did, however, report that they felt that they had been received nicely to the clinic.

Less than half of the study participants reported having one or more HWs or TSs who they felt they had a good relationship with. Patients living in rural or semi-urban areas more often reported having a good relationship with the TS than the patients living in urban areas.

Only a couple of patients reported that they had been treated badly by a HW or a TS. In addition some isolated incidences were reported from encounters the patients had had at the hospital. However, in the health clinics we visited only a couple patients reported that they had been treated badly by being yelled at by a HW when they came too late to the clinic to collect medicines. A female patient reported that she had been denied medicines since she came to the clinic a few hours too late. This patient reports that the HW did not want to listen to her explanation for why she came late to the clinic. The patient had to wait for 3 hours at the health clinic before the HW decided to give her medicines.

Being cared for

The patients described the term “being cared” for differently. Some patients thought that the main reason they had to come to the clinic every day, or once a week, to collect medicines was because the HWs and TSs cared for the patients. Several patients reported that having to come to the clinic every day to collect medicines was challenging for them due to e.g. poor physical condition, long travel distances and loss of daily income. Nevertheless, they reported that they believed they the main reason they had to come to the clinic every day was so the HWs/TSs could observe their condition. Many patients perceived this as a caring act from HWs/TSs who were concerned about the patients’ health.

A male patients, 36 years, is illustrating how he thinks having to come to collect medicines every day can be considered as a caring act from the HWs and TSs:

“It shows that they care for you, they want to know if you are progressing. If someone does not care for you they don’t even ask for you to come back, they can just give you the medicine and say you can go. But for them to be giving you that medicine and trying to know your progress it means that care about you and they don’t want you to die from a disease like TB.”

Some patients did, however, report that they believed the reason they had to come and collect medicines every day was because the HWs/TSs did not trust that the patients would take their medicines without being supervised.

Patients that were visited at home by a TS also perceived the visit from the TS as being cared for. A male patient, 35 years, is explaining how he is being cared for by his TS:

“He gives us a lot of attention; he never disappoints us, he gives the medicine in time and advises us to take the medicine from home so that in case we feel bad after taking the medicine we can find somewhere to sleep. (...) When you are sick, some people will not look at you as a human being, so they won’t care about you. But this treatment supporter treats me with care and gives a lot of attention.”

Another male patient, 45 years, is explaining how he experienced the TS coming to his home to visit him:

“I felt better, and everybody who knew me when I was very sick saw that I was picking up. You know when you are alone and you are sick, you can be more than sick when nobody is coming to see you, it is very important when someone is coming to see you, it motivates you and gives you morale.”

The patients who were visited at home by a TS did all report that they felt that they had been cared for by the TS. These patients reported being motivated to continue treatment. These patients also reported that the TS, together with family members, were the ones who motivated them the most to continue treatment.

The patients that had not been visited at home by a TS or a HW did not bring this up as an alternative as they did not know that TSs or HWs sometimes visited TB patients in their homes. The patients that collected their medicines at health clinics usually reported a family member or a friend as the most influential person related to their motivation to continue treatment.

6.5.2 The role of family and friends

The important role family members and friends regarding the aspect of care in the DOTS program was emphasised by the patients. Many of the study participants talked about their relationship to family, friends and community during treatment. This relationship was important for the study participants, and the way the patients were treated by family, friends and community was of great importance to them, and it affected their experience of being a TB patient.

The patients described different levels of support from family and friends. The patients' descriptions have been divided into three main levels.

Active support

About one third of the study participants reported having one or more family members that actively supported the patient in the treatment process. This active support was given through e.g. accompanying the patient to consultations, being present during consultations and helping the patient to remember information given about the disease and treatment, encouraging the patients to ask questions or asking questions to the HW/TS on behalf of the patient, helping the patient in daily tasks like e.g. personal hygiene and intake of meals, encouraging the patient by reminding the patient what the health professionals had advised and informed about, reminding the patients to take their medicines, arrange for the patient get to and from work and informing and including neighbours, friends and community in the patients situation.

These patients explained that they during the treatment process became more self-confident in the meetings with HWs and TSs. They felt comfortable asking questions and discussing concerns with HWs or TSs, and reported having few experiences of being treated badly by friends or by community members. On the contrary these participants reported that community members and friends were supportive and encouraging by visiting the patients and helping out with food-supplements if needed. These participants reported being open about the disease to friends and community, and some stated that the support and help from family and community was the most motivating factor from them to continue treatment.

A male patient, 34 years, is explaining how his family were active in supporting him and caring for him during the treatment:

“I saw that without my family maybe I could have died, because they made their efforts at least to take care of me (...) whatever I request from them, whenever I feel like I am lonely, somebody is there on the bed side, trying to entertain me, someone is trying to interview me, trying to tell stories.”

This patient was further explaining that when his condition improved after a couple of months on treatment he was telling his friends about his disease. He is explaining why he felt it was important to share his experiences with his friends:

“Some people hide, they hide saying: me, I can not disclose this to other people that I have this disease. But why should I hide? Who is going to assist me? It’s the people around you. If I share my views with other people, it’s from them that I am going to get help also. So if I hide then I am just killing myself.”

This patient, who at the time of the interview had 2 months left of the DOTS treatment, reported that he was now working as a teacher, and that his friends and community members treated him like they did before he got sick.

Acceptance

More than half of the study participants reported that their family members and friends accepted that the patient had TB. Patients commonly used the term ‘accepted’, and the patients reported that acceptance meant that family members did not discriminate the patient in any way, like e.g. isolating the patient or blaming the patient for getting sick with TB. However, acceptance by family and friends seldom resulted in family or friends actively participating in any parts of the treatment process. The patients reported coming to the clinic alone. Acceptance also meant that the TB and/or HIV status of the patient was not discussed with any friends, neighbours or the community members. Many patients reported that friends and community members seldom came to visit the patient, and the patients preferred not to disclose their TB status.

Many of the patients who reported that family members and friends accepted that they had TB, also reported being reluctant to ask questions or discuss their concerns with HW or TS. The patients reported that they followed instructions from HWs and TSs.

Discrimination

A few of the study participant experienced to be discriminated by family members. The discrimination was often referred to as being isolated in a separate room, and being scolded and blamed for having TB due to their previous lifestyle behaviour. These patients explained that they felt like a burden to their family. These patients also expressed feelings of

loneliness, and reported that they had only themselves to trust. Several of these patients referred God as being the motivational factor to continue treatment.

Most of these patients further reported that they did not ask HWs or TSs any questions. They reported that they did not want to be of any inconvenience to HWs and TSs, whom they could see were busy. These patients explained that they did not seek care or support from anyone they knew. They were determined to manage the disease on their own.

Although there were differences in how the patients experienced support and care from their family members, all the patients that were visited at home by a TS reported that they felt supported and encouraged to continue treatment regardless of the level of care from their family. These patients felt that they could ask the TS any questions. The patients that had a TS visiting them at home were often the same patients that had active support from their family members.

Several of the patients that consulted HWs or a TSs at a health clinic, and did not have any active support from family, reported that they did not feel comfortable to ask the HWs/TSs questions, and these patients expressed a need for more support and encouragement, even though their family members did accept that they had TB. Some of these patients reported that they had little or no contact with other people than the family during the treatment period and they were feeling lonely.

Trust

Some patients worried that they would die in the beginning of the treatment, and reported that although their family and friends provided care, and comforted them, they did not trust what their family members and friends told them.

A female patient, 27 is explaining how she felt when her friends came to see her when she was ill:

“One time in the morning I just woke up and found that a lot of people had come to see me, so I asked them “what have you come to see? Does it mean that am very sick? Then they said: no, it doesn’t mean that you are very sick, we have just come to see you. Then they just encouraged me that I would recover, but I knew that I was

sick because I was very thin, I lost weight, I had no appetite, no blood, and things were not ok.”

This female patient believed that her condition has worsened since so many of her friends had come to see her. She explained that it was difficult for her to trust what family and friends told her because she was feeling weak and she was afraid to die.

Several patients explained that what helped them through the times when they had doubts they would be cured from TB, was to talk to previous TB patients that had experienced the same as they experienced now.

6.5.3 Patient support groups

TB patients support groups were mentioned among some HWs and TSs as an alternative for TB patients to get information and care. When the researcher did some further inquiries about what a TB patient support group was and how it worked, it was discovered that TB patient support groups most commonly were groups that consisted of former TB patients that now worked as TS. Support groups for TB patients that were on treatment were not common in the study areas.

Several patients expressed a need for a forum where TB patients could meet and express their concerns, learn from each other and give each other advice. It was suggested by a few patients that a forum like this should be lead by a HW or a TS who had knowledge about TB and TB treatment. A few patients mentioned that they knew that support groups for HIV patients existed, but that they did not know of any support groups for TB patients. The patients expressed a need for support groups for TB patients, similar to the support groups that exist for HIV patients.

The researcher came in contact with an organization called TWIP (see chapter 4.8.5), that provided care and support for people aged 18-30 years who were infected with HIV, TB or other communicable diseases. Two of the younger study participants who expressed a strong need for care and support were put in contact with this organization.

6.5.4 Summary

In this section we have explored how patients seek and receive care in a DOTS program. We have looked into what patients perceive as good care, and we have explored who is providing care to the patients.

Patients reported that being received nicely and friendly by a HW or a TS involved being greeted and being given medicines without being blamed for having TB. Whether or not the patients were asked any questions from the HW or TS, or whether or not the patients felt free to ask any questions to the HW or TS, did not affect the patients' perception of the HW or TS receiving them nicely and friendly. Being received nicely and friendly was not necessarily related to patients' perception of being cared for in a good way.

Patients who had consultation with HWs and TSs who had a good heart felt that they were cared for. Patients who had a TS visiting them in their home also felt that they were cared for very well.

TB patients reported being supported and receiving care from family and friends differently. Three levels of support and care from family and friends were recognized: 1. active support, 2. acceptance and 3. discrimination. Most of the patients experienced that their family members accepted that they had TB, but that the family members did not give any active support or care to the patient.

Several patients expressed a need for more support through support groups or similar where patients could meet and express concerns and share experiences and advice.

Patients who were followed up at home had their care needs fulfilled. Few of the patients who collected medicines at a health clinic had their care needs fulfilled.

6.6 Not taking part in decision making

This section will look at how patients described participation in the decision making process regarding their own treatment. This was important related to how patients experienced taking part in a DOTS program.

Many of the participants in the study explained that they found it difficult to come to the clinic every day to collect medicines due to among other poor physical condition, long distances and loss of daily income. Some of the patients further reported that they had asked the HWs/TSs at their respective clinic if it was possible to come to the clinic to collect medicines once per week instead of every day. Only one participant who had requested this got his request granted and could collect his medicines once per week. Most of the patients did, however, get their request denied, and had to continue to come and collect medicines every day. These patients reported that they were not given any reason as to why their request was denied. Some reported that they were just told by the HW or TS that “this is how we do it here”.

Several of the participants reported that they did not ask the HW/TS if they could come once per week instead of every day in fear of getting refused further treatment.

This quote from a woman, 28 years old, from a semi-urban area, is illustrating the thoughts some of the patients had on their possibility to influence their DOTS schedule:

“We don’t have a say or power to say no to the dates given. We can not control the health workers. (...) If you complain the HW will say it’s up to you; you are the one who is sick, so if you feel like protesting it will be your problem if you don’t get better.”

This woman is further explaining that she is afraid that she will not be allowed treatment if she doesn’t follow the instructions from the HWs/TSs.

“Even if you miss one day of appointment you won’t be friends with the nurses. If you stop and then come back they won’t pay attention to you, they won’t look after you.”

When this woman was asked by the researcher if this had actually happened to her, she denied this. She explained that she had heard stories from other patients who had been refused treatment when they did not show up for an appointment. She was afraid the same could happen to her. The quote showing the woman’s fear of being refused treatment illustrates how several other participants described how they felt. The majority of the patients further explained that they did not expect to be included in decision making regarding their treatment schedule, only a few patients discussed their schedule with HWs or TSs. What was

common for the patients who discussed and planned their treatment schedule with HWs or TSs, was that they had good knowledge about TB and the DOTS treatment, and they had active support from family members.

The study participants had different thoughts about why they had to come to the clinic at certain times and intervals. Some believed it was to be observed by the HWs and TSs. Other believed it was because the HW/TS did not trust them to take their medicines, and some believed it was because there was not sufficient supply of medicines at the health clinic. Although they had different opinion about the reasons they had to come, the participants commonly reported that they had not been told the reason as to why they had to come to the clinic so often.

Several patients reported that they faced a number of challenges related to e.g. transport costs, loss of daily income and child-care due to the treatment schedule, however, most of the patients reported that they did not want to protest against the schedule as they feared sanctions related to access to treatment.

7. Discussion of findings

In the previous chapter the findings from this study were presented in relation to the objectives of the study. In this discussion chapter the findings will be discussed in relation to a wider context by answering the questions: what is good and poor communication in this context? And what are the implications of good and poor communication?

The positive experiences from patients who were followed up at home by a TS were describing a context where the conditions for good communication were optimal. The communication was patient-centred and the patients felt cared for. The patients are giving the health professionals inputs on what is important for them in good communication by sharing their good experiences like they have in this study. The findings from this study presented different experiences from TB patients, and the most distinctive differences were between the patients who were followed up at home by a TS in rural and semi-urban areas and the patients who were followed up at a health clinic by a HW or a TS in urban areas.

Although not all TB patients in the Copperbelt province of Zambia will have the opportunity to be followed up by a TS or a HW at home during a DOTS program, there are several areas in the interpersonal communication setting in a health clinic that can be adjusted and improved based on the experiences and opinions shared by the participants in this study.

7.1 What is poor communication in this context?

The term poor communication is not easily defined. How different people define poor communication depends on the context communication is happening in, and it depends to a large degree on the expectations the people in the interaction bring with them. The findings in this study suggest that several TB patients expect to be blamed for getting sick with TB, and they expect to be treated without empathy and dignity by the HWs and TSs. Some patients reported that they had heard stories about TB patients who had been treated badly by HWs or TSs by being scolded or yelled at in front of other TB patients, and therefore the participants in this study reported that they did not have any expectations of being welcomed nicely or friendly by HWs or TSs. When the patients then were welcomed to the health clinic without being blamed for having TB, and they were not scolded or yelled at in any way,

many patients experienced this as being welcomed nicely and friendly by HWs and TSs. The question is, however, whether the patients' experiences of being welcomed nicely and friendly actually mean that the communication taking place is good communication?

The majority of the patients reported that they had many different concerns, and the patients expressed a need to receive more information and advice regarding how to manage life. The patients had incomplete knowledge on TB and the treatment regime, and various misconceptions circulated among the TB patients. Instructions on not to smoke, not to drink alcohol, not to have sex and to take medicines every day were given to the patients without any further explanation as to why it was important not to smoke, not to drink alcohol, not to have sex or not to interrupt treatment. The lack of explanations as to why they should not smoke or drink alcohol or have sex led many patients to believing having sex, smoking and drinking alcohol was the reason they got infected with TB in the first place, and several patients reported that they therefore blamed themselves for getting TB. Several patients further reported that they were not taking part in any decision making regarding their own treatment schedule, and that they felt they had no power to say no, or to protest to the instructions they were given by the HWs or TSs. The interesting fact, however, was that the patients in most cases did not ask questions or discuss their concerns with the HWs or TSs even if they had many unanswered questions. And the HWs and TSs did not ask the patients about their concerns or worries. This suggests that something is hindering open and good communication between patients and HWs/TSs.

The patients reported that instead of asking HWs and TSs they asked unskilled personnel like e.g. the gardener at the health clinic, friends, neighbours and community members for information and advice. This resulted in patients receiving different and sometimes contradictory advice from different sources. Several patients explained that they did not know whom to trust, and this again led to increased frustrations and concerns.

Despite all the above mentioned aspects, the majority of the patients reported that they were received friendly and nicely by HWs and TSs at the health clinic. If one were to define the quality of the communication as good or poor in this case based on only the patients statements of being received nicely and friendly, the communication between patients and HW/TS could in fact be defined as good by patients or by HWs/TSs. This clearly illustrates the importance of taking the patients expectations into consideration when exploring issues

like good and poor communication. Patients, who have never experienced good communication in the sense of being treated with respect and dignity and by having their right to autonomy preserved, don't have anything to compare the communication they have with HWs and TSs with. Hence the communication they experience is perceived good compared to the fact that they expected to be treated badly by e.g. being blamed for having TB or by being scolded by the HWs and TSs.

HWs and TSs had a different view than patients regarding what they perceived as good and poor communication. HWs and TSs were not participating in formal interviews or FGD in this study, however, the researcher had several informal conversations with HWs and TSs during the data collection period, and the researcher also participated as an observer in the one week health communication skills training for HWs and TSs provided by CHEP. In this training course the HWs and TSs perception and experiences of good and poor communication were discussed. The HWs and TSs explained that communication with TB patients could be challenging. They reported that patients who did not listen to them or patients who showed signs of anger or frustration by being rude to the HW or TS were the most challenging ones. HWs and TSs expressed a need to improve skills related to how they could handle conflicts in the communication with patients and with co-workers.

The patients' perspective of communication on one side and the HWs and TSs perspective on the other side clearly illustrates how the context communication is happening in is important for how communication is being perceived and how communication is taking place. The internal context refers to what the patients and HWs/TSs bring into the communication process based on e.g. their expectations and experiences. The patients have their predefined expectations based on stories they have heard from other people regarding the DOTS treatment and their own previous experiences from encounters with the health system. The HWs and TSs have their previous experiences of situations they found difficult to handle due to patients who would not listen to them or who were angry or frustrated.

When these two parts are describing the communication setting they are describing it based on the internal context that is valid for them. E.g. a HW or a TS might describe the communication as good if the patients are not angry, frustrated and if the patients say that they understand what the HW or TS is telling them. The fact that patients do not ask questions or discuss their concerns with the HW or TS might not be perceived as poor communication by the HWs or TSs. This might suggest that when HWs and TSs do not

experience any confrontations or explicit dissatisfaction from patients, the communication with patients is perceived as good. If the patients, on the other side, do not experience any accusations, scolding or yelling in communication with HWs and TSs they perceive the communication as good.

What good and poor communication comprises for different people will depend on their expectations and on previous experiences. The question then is if it is possible to make a statement on whether or not the communication is good or poor. The matter of concern here is, however, not if the communication is perceived as good or poor by different people. The matter of concern is how different aspects in communication have different implications for the patients. If the implications are poor treatment adherence, low TB detection rate, lack of support from family and friends, insecurity and fear, increased stigma and feelings of guilt and shame among the patients - then it is safe to assume that something in the communication process is not working as it should, hence the communication can be defined as poor. Although it is important to listen to what the patients perceive as good and poor communication, their statements alone can not define whether or not the communication is good or poor.

Aspects of poor communication

Making sense

One aspect that stands out in this study is the patients' need to make sense of what they have been instructed and advised by the HWs or TSs. The fact that patients have a need to make sense of the information and advice they get is well documented in the literature. Helman (43) is stating that the treatment and diagnosis must make sense to the patients based on the patients "lay view of ill health" (43) and their understanding the disease. He further states that it is important to acknowledge the patients' experiences and interpretation of their own condition (43). This can be seen in connection to how literature is focusing on explanatory models. It is suggested that patients and health professionals have different explanatory models, and if the information to the patients is given by HWs or TSs who have a different explanatory models than the patient, the patients will struggle to make sense of the information and advice they get. DOTS is based in a Western bio-medical explanatory model, which can be understood and adopted by HWs and TSs in an African context who have some medical training (43). However, patients have as we can see from the findings of

this study, problems with making sense of the information they are given as they use different and more traditional explanatory models than the HWs, and sometimes also the TSs. The fact that patients use different explanatory models than HWs/TSs does not mean that they cannot make sense of a DOTS program and the information they get, but it puts an extra challenge on the HWs and TSs who have to explore what information and advice the patients need to have explained further. Patients are often trying to come up with logic explanations to advice they have been given. This can lead to misunderstandings. Like e.g. the male patient in this study who was advised by a HW not to have sex in the beginning of treatment. He thought that having sex whilst on treatment could reduce his chances of getting healed as having sex would mean that he was using proteins (sperm). He had been told that it was important to eat a lot of proteins during treatment and using proteins by having sex would therefore impede treatment. Why the HW advised the patients not to have sex is unknown, but it is common that patients are advised not to have sex. The patient did mention that the HW had asked the patient to take a HIV test as the patient did not know his HIV status.

The findings in this study regarding patients' need to make sense of the information they are given, is supported by the findings in the study done in Ethiopia in 2003 by Sagbakken, where the issue of HWs and patients having different explanatory models, and the patients' needs of making sense of the information is also discussed (51).

How patients struggle to make sense of the information they are given is further illustrated by the use of the term "airborne disease". The patients reported that they had been told by the HWs/TSs that TB was an airborne disease caused by bacteria. They did, however, not know what airborne disease meant. This resulted in misconception regarding how TB transmits from one person to another, and this misconception resulted in patients making decisions based on a wrong understanding of what airborne disease is. Several patients believed TB was transmitted to others if they shared a drinking container with someone else, or that TB was transmitted by working with e.g. charcoal or poultry. Some patients therefore decided to quit their job. Others stopped associating with friends in fear of infecting them with TB. None of the patients had been informed that they could not infect other people after they had been on treatment for two weeks. Several patients reported that they isolated themselves from other people as they believed that TB infected throughout the whole treatment period. One patient

explained that he moved away from his wife and newborn child for the whole eight month treatment out of fear of infecting them with TB.

Since some TB patients did not understand how TB infected and did not understand the close connection between TB and HIV, some patients reported postponing HIV testing and counselling and thereby risk transmitting disease to others. Patients also reported that they worried about symptoms and side-effects of drugs that actually were common when on TB treatment, but the patients had not been informed about the side-effects, hence some patients chose to quit DOTS treatment and seek help from traditional healers due to the side-effects of the drugs. This resulted in interruption of treatment, delayed TB treatment and an increased risk of spreading TB. The inconsistent advice patients received from HWs, TSs, friends, and traditional healers resulted in frustration and the patients had problems in trusting the information they got from the different sources.

The reasons for why HWs and TSs seldom informed the patients about why they should or should not follow certain advice, and why they did not give more detailed information regarding TB and the treatment has not been further explored in this study. However, the fact that they seldom gave this detailed information can be linked to their internal understanding of communication. If the patients did not ask questions, or did not express any discontent when they did not receive the information, the HWs and TSs might have assumed that the patients knew, or did not need to know, the reasons behind the HWs/TSs advice and information.

Power structures

Kleinman (43) is describing that in the clinical consultation there is a transaction between the patients' lay explanatory models and the health professionals' explanatory models. It is also stated that in the consultation there is a "transaction between two parties separated by the differences in power, both social and symbolic" (43). The differences are based on e.g. gender, age, race and social class. In this study the issue of power differences between the patients and the HWs and the TSs was quite visible, especially in the consultations taking place at a health clinic. The HWs and TSs in one of the health clinics reported that they usually waited until there were around ten patients in line before they distributed medicines. This was also observed by the researcher. One can argue that having people waiting in a line for a certain amount of time before starting distribution of medicines is a way of

demonstrating power. The fact that often four to five HWs or TSs were seated next to each other when distributing medicines can also be argued to be a way of demonstrating power over the patients. The HWs and the TSs intentions behind the decisions to have patients wait some time before they received medicines, and the decision to organize the HWs and TSs the way they did by having four to five HWs and TSs seated next to each other when only one or two HWs/TSs were needed to distribute medicines, was not explored further in this study. It is nevertheless interesting to notice that the patients themselves reacted to the fact that several HWs and TSs were seated next to each other when only one or two of the HWs/TSs were distributing the medicines. Patients reported feeling intimidated, and that this resulted in them not asking questions or discussing their concerns with the HWs or TSs. The inferiority of the patients may give the HWs and TSs the impression that they are dealing with “non-problem” patients since the patients do not question the routines and organization of the DOTS treatment. The patients’ reactions can therefore be perceived by HWs and TSs as a confirmation that their actions and organization of the DOTS treatment are appropriate.

Regardless of what the HWs or the TSs intentions were, e.g. if they organized themselves in this way due to safety issues or whether it was in order to demonstrate power, the results was that patients did not ask questions. HWs and TSs usually gave information only in the first consultation, but expressed that they wanted the patients to ask them questions. This suggests that HWs and TSs were not aware of how their actions and choices influence the communication process between themselves and the patients.

Another area where differences in power was conspicuous was regarding the patients opportunity to take part in the decision making process of their own treatment schedule. Several patients explained that they felt they had no influence over their treatment schedule. They reported that they had asked the HW or TS if they could come to the clinic to collect medicines e.g. once per week instead of every day. The patients explained that coming to the clinic every day resulted in loss of daily income, unaffordable travel costs and physical exhaustion. Despite the patients’ efforts to influence their own treatment schedule, the HWs and TSs usually refused to meet the patients’ requests without giving a proper explanation for this. Several patients reported that they feared they would not receive medicines or receive treatment if they objected to the HWs or TSs decisions.

The differences in power between the HWs, TSs and the patients reflected a difference in social class. This resulted in patients not asking questions and patients not objecting to the e.g. the treatment schedule. Some of the patients received medicines once per week, it was, however, not clear to the patients why some of them could collect medicines once per week whilst other had to collect medicines every day. The effects of the differences in power were that patients had a fear of repercussions if they demanded any changes in their treatment schedule and patients and their families suffered due to reduced monetary income since it took a longer time for the patients to recover physically as they had to travel to the clinic every day. Lack of income also resulted in a struggle to provide enough food for the patients and for their families. In this study several patients reported that although they did not have the opportunity to take part in decision making regarding their own treatment schedule, they had not considered stopping treatment.

The power differences further affect the aspect of trust. The patients are undergoing a difficult and challenging treatment, and it is therefore important that they trust the information they are given by the HWs and the TSs. In order to trust the HWs and the TSs the patients need to see them as “competent, sincere and caring individuals” (54). If the patients feel inferior to the HWs and the TSs it will be difficult to establish a common understanding and a level of trust that is needed for the patients to adhere to treatment (54). HWs and TSs are perceived as powerful due to the social class and also due to the knowledge they have concerning TB. It is, however, important that the patients are recognized for their expertise. They are the ones who are sick, and know best what is going on in their body (54). If the HWs and TSs do not see the patients as the experts they are it will be difficult for the patients to trust the HWs and TSs. Several patients do at the same time have a profound respect for TSs and HWs as they possess a power over the patients’ possibilities to live. Several patients feel that they have to do as the HWs and TSs tell them to do, or they risk sanctions and being denied treatment. And without treatment the patients know that they will die.

Involvement of family

More than half of the patients reported that their family accepted that they suffered from TB. Acceptance did, however, not imply that the family gave any active support to the patients. Acceptance can, based on the patients’ statements, therefore be described as the absence of

discrimination. Patients who had acceptance from their family reported that they seldom asked questions or discussed any of their concerns with their family, HWs or TSs. These patients also reported that they were not open about their disease to friends and people in the community. Patients who had active support from family and friends reported being open about the disease to friends and community, and the patients felt that they could ask HWs and TSs any questions.

The patients who had acceptance from their family and the patients who experienced discrimination from their family, can be described as being more passive in the consultations with HWs and TSs than the patients who had active support. This passivity suggests that for some patients it was important to be perceived as a complying patient. This can also be seen in relation to the differences in power and the patients' fear of being refused treatment if they did not oblige to the HWs and TSs instructions. The patients who have active support from home did not express this fear of sanctions if they did not oblige to the instructions by HWs or TSs. The patients who had active support from their families can be described as more assertive in the consultation with HWs and TSs. They were self-confident and discussed their treatment schedule and made plans together with the HWs and TSs.

Northouse and Northouse, is describing the importance of establishing a relationship between the health professionals and the patients' families, and the importance of establishing a relationship between the patients and their families. Northouse and Northouse further state that these relationships, together with the patient-health professional relationship and the health professional-health professional relationship, are central to communication in health care settings (54). Family members have been credited to play a significant role in the patients' health behaviours and their ability to cope with their illness. The patients' families have been proven to be important for the level of psychological distress the patients experience in connection to illness. In a long term treatment like DOTS the relationship between patients and their families can, however, be fragile as the illness of one family member disrupts the family members roles (54).

Patients had concerns related to no longer being able to fulfil the roles they had before they got sick. Many patients reported that family members and friends did not always understand why the patients could not fulfil his/her role any more. Several patients also reported that they found it difficult to meet the expectations of the family members and at the same time

follow the advice given by HWs and TSs. These aspects can be seen in relation to the different levels of support the patients receive from their families. If the family members do not understand why the patients cannot fulfil their roles like they used to, and the patients are unable to explain why they cannot fulfil their role, it can be difficult for the family members to give the patients active support during their treatment. This can lead to conflicts in the family, and the patient is left without support in the treatment. This results in a patient who is passive in the consultations with HWs and TSs, and who does not share his/her experiences with friends or community members.

It is important that HWs and TSs are aware of the difficult situations that may occur in families when one of the family members gets sick. The HW or TS can be the one who can bring the family together again by including the family members in the treatment of the patient and by explaining why the treatment is important and how the treatment affects the patient. In this study we have seen the great advantage of including the family members in the DOTS treatment of the patients. The patients became assertive and open in the consultations with HWs and TSs, and this further suggests that their prospects for a successful treatment increased.

Asking questions

The fact that many patients seldom asked questions or discussed their concerns with HWs and TSs at health clinics can be seen as a result of poor communication. When the aspects of making sense, power structures and involvement of family were not properly managed by HWs and TSs it resulted in passive patients who seldom asked questions, did not discuss concerns and did not share their experiences with friends and communities.

Although many patients seldom asked questions or discussed their concerns with HWs or TSs, there were some patients who felt that they could ask questions as long as the questions were related to medicines or side-effects of the drugs like e.g. headache or nausea. Other concerns that were related to e.g. sexual relations were rarely discussed with HWs or TSs. The patients did, however, bring the issue up in several interviews. The fact that the patients did not discuss these matters with HWs and TSs suggests that there is a fear of moral judgement by the HWs and TSs. Instructions of not to have sex often came together with instructions of not to smoke or drink alcohol. It is unknown why the HWs and TSs gave many patients the advice of not to have sex during treatment.

When the HWs/TSs only asks the patients questions related to their physical condition they signal that these are the only questions that are acceptable to discuss. The implications poor communication has on the patients, and on public health will be discussed in chapter 7.3.

7.2 What is good communication in this context?

In this study there was a clear difference between how TB patients that received their medicines and had consultations at a health clinic experienced participating in a DOTS program compared to patients who had been followed up by a TS at home in the initial phase experienced participating in a DOTS program.

The patients in this study described three main categories of consultations with the HWs and TSs. The first category that many patients described was in a health clinic setting: the patients arrived, waited in line, and received their medicines without any further conversation with the HWs or TSs. The HWs or TSs seldom asked the patients any questions, and the patients seldom asked the HWs or TSs any questions. The second category of consultation was also in a health clinic setting: the patients arrived, waited in line, when it was their turn the HW or TS asked the patients about their physical condition and whether or not they had experienced any side-effects of the drugs. The patients then sometimes explained about the side-effects they had experienced and received advice for how to manage the side effects. The conversation regarding side-effects and physical symptoms was conducted in front of all the other patients that waited in line, and in front of up to five HWs or TSs. The patients further received their medicines and left. The third category of consultation described by the patients was in a home-based care setting. The TSs usually came to the patients' homes where they distributed medicines and had private conversations with the patients regarding e.g. side-effects of drugs and other concerns that were not related to physical symptoms or side-effects. This category was described as very encouraging and helpful by the patients who experienced this type of consultations. The patients were positive towards the TSs and HWs, and several of these patients reported that the TSs were the ones who had motivated them the most to continue treatment. The patients who had been followed up at home by a TS did sometimes have consultations at a health clinic in order to collect medicines. The patients did, however, explain that they usually asked questions and discussed their concerns with the TS at home when the TS came to visit.

About 1/3 of the patients were followed up at home during the whole or parts of the initial phase of treatment and about 2/3 of the patients collected medicines from a health clinic. The statements and opinions of the patients who were followed up at home by a TS were unison and clear. Being followed up at home by a TS who lived nearby the patient had several positive outcomes for the patients. This will be discussed in chapter 7.4. Several patients knew the TS from before and therefore already had a relationship to the TS. Other patients were familiar to the TS, who often was a member of their community. The TSs usually came from the same social class as the patients, which resulted in a balanced power level in the relationship. The TS had experienced what the TB patients were experiencing now, and this made the patients feel understood by the TS.

It is important to emphasise that the use of TSs in a DOTS program requires thorough training of TSs. Repeated training and close follow-up and supervision by HWs at health clinics is important to assure that the patients are provided with correct information and medicines. TSs do not have a professional health education like HWs, and the HWs role in the DOTS program must not be undermined. The HWs assign tasks to the TSs, and the TSs reports back to the HWs or the DOTS corner nurse. The health clinics play an important and central role in a DOTS program, and without proper follow-up and supervision of TSs from HWs in the health clinics the quality of the services to the patients can be reduced. A study exploring the role of home based care in Lusaka in 1999, supported the findings from this study, namely that many patients were satisfied with home based care. Shortcomings of the HBC programs were reported to be poor record keeping and failure to meet recommended standards for TB treatment. Another weakness was reported to be limited supervision of care givers by medical staff or coordinators. This points out the importance of close supervision and follow-up of TSs.

Aspects of good communication

Having a good heart

The patients did not take for granted that the HWs or TSs they encountered during the DOTS program had what they referred to as “good hearts”. The patients who had consultations with HWs or TSs who had a good heart described this as something extraordinary. Several patients explained that they felt lucky to meet a person who attended to them in such a nice way by listening to them and appreciating them even though they suffered from TB. This

gave the impression that many patients did not feel that they deserved to be treated that well and this can be seen in connection to the feelings of shame and guilt for having TB several patients described. The patients' feelings of shame and guilt influence the expectations the patients bring with them into the encounter with the HWs or TSs. The patients who were visited at home by a TS reported feeling cared for, and reported that their need for information and advice was catered for.

Patients who had never experienced a TS or HW visiting them at home did not bring this alternative up when discussing what they perceived as good communication. These patients brought up other alternatives for improving communication like e.g. having allocated days where they could come to the health clinic to ask questions, creating patient support groups similar to support groups for HIV/AIDS patients where patients could share experiences and information, and making arrangements for private consultation at the health clinics.

TSs as peer educators

One of the most important aspects of good communication that the patients pointed out was the use of TSs in the DOTS program. The patients reported that they recognized themselves in the TSs who had the same background and came from the same social class as themselves. TSs were perceived as peers, and this resulted in good communication between patients and TSs.

The TSs were reported to give explanations on issues regarding TB in a way the patients could understand. The patients also reported that they felt the TS understood the patients concerns and worries. These issues are related to the concept of "making sense". The patients and the TS are often using similar explanatory models, hence the patients are able to make sense out of the information given to them by a TS. The TSs are using their own experiences when explaining issues to the patients, this makes the information specific and tangible. HWs who have a different background than the patients and are using a different explanatory model are more abstract in the way they describe and explain issues to the patients. This suggests that patients therefore establish a closer and more open relationship to the TSs that are more specific in their explanations than the HWs.

Involvement of family

When HWs/TSs are visiting the patients in their homes the HWs/TSs will also encounter the patients family members. In this study it was reported that the TSs consulted the patients' family members and addressed different issues that the family needed advice on like e.g. how to prevent transmission of TB to other family members, how to best manage side-effects of drugs, how to manage sexual relations and how to efficiently organize for the patients to return to work when the patients physical and mental condition allowed for it. This level of involvement of family members was not seen among the patients who consulted HWs and TSs at a health clinic. Many patients reported that they on some occasions had sent family members to collect medicines for them. Several patients reported that in these cases HWs or TSs seldom provided the family members with any information and seldom asked the family members any questions. This suggests that it is not a common practice in health clinics to involve family members in the treatment process.

The importance of involvement of family members is described by Northouse and Northouse (54) who are referring to how a significant other e.g. a family member or a good friend plays an important role in the patients' health behaviours and their ability to cope with their illness. The patients' families have been proven to be important for the level of psychological distress the patients experience in connection to illness. The involvement of family members was perceived as important and helpful by the patients. The patients reported that they received more active support and encouragement from their family members after the HW or TS had talked to the family members.

The findings from this study further suggests that involvement of family members will actually reduce the work-load of the HWs and the TSs as family member can take over some of the responsibility the HWs and TSs have. The family member can observe and support the patient in taking medicines every day.

Pro-active communication

In the health clinics located in semi-urban and rural areas a more pro-active approach by the HWs and TSs was observed. A pro-active approach can be explained by putting efforts into controlling a situation by causing something to happen rather than waiting to respond to it after it happens. This could be seen particularly in connection to the efforts made by TSs and HWs in the rural and semi-urban areas towards preventing patients to interrupt treatment.

The home-based care was one of the efforts put in to prevent interruption of treatment and this was by the patients experienced as a caring act from the HWs and TSs.

In the urban health clinics TSs were used mainly to trace patient who did not show up for appointments. When a patient did not come for treatment, a TS or a HW was sent out to trace the patient. This can be described as a more passive approach, where the HWs and TSs are waiting to respond until the patient actually has interrupted treatment or defaulted.

The HWs and TSs in the urban and semi-urban areas reported that the pro-active approach resulted in fewer defaulters. The actual difference in the defaulting rate with and without a pro-active approach, and the actual defaulting rate in rural and semi-urban areas compared to urban areas have, however, not been explored in this study.

7.3 What are the implications of poor communication?

Individual level

When patients were met with poor communication that involved difficulties to make sense of the information and advice given to them, power differences and not involving family members the patients' first reaction was to not ask questions or discuss concerns with the HWs or TSs.

Several patients had unanswered questions and concerns that they needed to discuss with someone, and often these questions and concerns were discussed with friends or peers that had little accurate knowledge regarding TB and the TB treatment. When the patients are not being explained the reasons for why they should follow certain instruction, they can not make sense of the information they have received. Lay beliefs and misconceptions that circulate in the communities are then upheld since the background for certain advice and information is not brought out in the open. Misconceptions regarding the connection between TB and HIV were common. Some patients reported that it was a common belief in the community that if a patient was infected and sick with TB he/she was also infected with HIV. This resulted in reactions and judgements by friends and community members that were perceived as discriminating by some of the patients. The fear of the unknown plays an important role in the discrimination and judgement that TB patients are exposed to.

The fact that patients sometimes received wrong and inconsistent advice from different sources also resulted in patients making wrong decisions. Long separation periods from their families, interrupting treatment and postponing HIV testing and counselling were some of the decisions patients made based on wrong information and advice.

Patients being judged and discriminated by their friends and the communities led to feelings of loneliness and sadness. Many patients blamed themselves for getting sick with TB. This resulted in patients distancing themselves from other people, and the patients did not share their experience as TB patients with other people. This suppression of their status as TB patients and/or HIV patients could lead to suspicion and scepticism from people in the communities. Hence, discussing TB and HIV can be considered a social taboo and this is leading to unwillingness among many people to get tested for TB and HIV. This can partly explain the low detection rate in Zambia (53%). The DOTS strategy relies on self-presentation of patients with chronic cough, and if patients are unwilling to talk about TB it is also unlikely that they are willing to get tested for TB.

Public health level

The literature review established the correlation between poor communication and poor treatment adherence. In this study information on the number of patients adhering to treatment and the number of patients not adhering to treatment was not obtained. This study can not give any clear indication as to whether the poor communication taking place in study sites of this study affects treatment adherence or not. All the patients that were included in the study were adhering since they attended the clinic. But, the findings still indicate that not all patients experience good communication. Whether or not patients that has defaulted treatment did this due to poor communication is unknown.

The findings in this study indicate that poor communication can be related to a low detection rate (53% in Zambia). The low detection rate makes TB a difficult disease to control, even though treatment adherence has improved the recent years.

7.4 What are the implications of good communication?

Individual level

Patients who experienced good communication reported that they had an open relationship with the TSs and HWs. They felt that they could ask questions and discuss private concerns with the HWs and TSs. Involvement of family also led to patients having less worries, and the patients experienced less judgments and discrimination from friends and community than the patients where the family was not involved in the treatment. Good communication involved patients participating in decision making regarding their own treatment schedule, which again resulted in assertiveness and a feeling of being in control of their own life. Being respected for their wishes and opinions was a result of being treated with dignity and humanity.

Patients who experienced good communication reported to be encouraged and motivated to continue treatment. These patients reported that they were determined to finish the whole treatment course. Patients who had consultations at home also explained that they had financial benefits as they did not have to spend money on transport to the health clinic every day.

Public health level

Good communication can, according to the findings in this study, be connected to improved treatment adherence and increased TB detection rates. Good communication in the DOTS program resulted in patients and their families talking about the disease to friends and community, and this again resulted in openness about TB that had reduced the fear friends and community members had of TB, and therefore they came visit the patient. More openness and less discrimination resulted in people being informed about TB, which can result in increased TB detection rates as people recognize symptoms of TB and they feel more responsible for getting tested for TB, hence the detection rate can increase.

The findings in this study further suggest that individual and patients-centred care solves many of the patients' concerns and worries. Barriers to treatment adherence like financial burden and organization of treatment and care can be overcome by good communication. If a patient loses his daily income due to the fact that he has to collect his medicines every day

from the health clinic, the patient might interrupt treatment. If the patient is able to communicate his concern to the HW or TS the problem can be solved by either letting the patient collect his/her medicines at another time of the day, or the HW or TS can include a family member into the treatment so the family member can support and encourage the patients to take his/her medicines every day. In this way the patient can still attend his work and ensure daily income to himself and his family.

With good communication many barriers to treatment adherence can be overcome, it does however require that HWs and TSs have good communication skills and are aware of the patients' needs. The situation that is described in this chapter is complex. Many factors influence how HWs and TSs communicate with patients. Improvement of HWs and TSs communication skills is one of the interventions that can contribute to better communication in a DOTS program and stimulate to more openness about TB in the communities.

8. Conclusions and possible recommendations

Conclusions

Exploring the patients' experiences of participating in a DOTS program provided valuable information regarding what aspects of communication are working well and what aspects need to be strengthened.

Patients who were followed up at home by a TS during the whole or parts of the DOTS treatment had their needs for information, advice and care catered for by the TS. The patients discussed and planned their treatment regime with the TS. The patients took part in decision making regarding their own treatment, which ensured the patients' rights to dignity and autonomy.

The TSs' involvement of the patients' families in the DOTS treatment, and the use of TSs whom the patients related to as equals, resulted in assertive patients who asked questions and discussed their concerns and worries with family members and TSs. The patients were open about their disease to friends and community. The patients' openness about TB resulted in less discrimination and judgement from friends and community, and the patients were treated with respect and dignity by TSs, family, friends and community. Patients were motivated to continue treatment without interruption.

Few patients who were attending a health clinic on a daily or weekly basis had their needs for information, advice and care catered for although the patients reported being received nicely and friendly by the HWs and TSs. The patients seldom asked questions or discussed their concerns and worries with HWs or TSs. Patients had difficulties in making sense of the information given to them by HWs and TSs. The HWs' and TSs' organization of the DOTS corner at health clinics often resulted in a lack of privacy for consultation and a strong perception of differences in power. The patients' experiences of inferiority resulted in patients not discussing their treatment schedule with the HWs or TSs for fear of treatment sanctions. Patients were passive in the interaction with HWs, TSs and friends, and patients preferred to not disclose their TB and/or HIV status to friends and community. Not being open about their disease contributed to a general lack of knowledge about the disease in the communities, and judgements and discrimination from friends and community were

common. Patients had feelings of loneliness and hopelessness, they were, however, motivated to continue treatment as they knew that this was their only chance for survival.

Poor communication has implications not only for the individual, but also for public health. Low TB detection rates can partly be explained by the level of discrimination in the society. When people are unwilling to talk about the disease, this reduces people's willingness to get tested for the disease.

The correlation between poor communication and treatment adherence is well known in literature. This study does however bring new knowledge regarding what areas of communication that is problematic for the patients, and the study points out the possible correlation between poor communication in the DOTS program and low TB detection rates. The study further brings new knowledge regarding what patients experience as good communication. This knowledge can be valuable in the development of training programs directed at improving communication skills of HWs and TSs. By knowing what the patients perceive as difficult in the communication, and what they perceive as positive the training of HWs and TSs can more specifically target these aspects. This study also addresses what the term patient-centred communications means in this context. In order for the DOTS program to be patient-centred, the patients' right to autonomy must be preserved. The patients must be included in decision making and individual plans must be made.

On a public health level a good relationship and good communication between patients and HWs/TSs indicates that good treatment adherence is more obtainable and that TB detection rates can increase as there is more openness regarding TB and HIV/AIDS in the communities. Better adherence and increased detection rate will help to control TB and slow down the development of drug resistant TB.

Possible recommendations

In this study we discovered several specific areas that can be strengthened in order to make a foundation in the DOTS program that encourages good and patient-centred communication. Improved arrangements that ensure privacy and reduce the perception of differences in power at health clinics can be made without extensive financial expenses, however, improved communication skills among HWs and TSs that includes an awareness of how patients perceive the communication with HWs and TSs is needed.

Areas that proved to be important in good communication were:

The use of TSs as DOTS support for the patients: the use of TSs should be enhanced and the positive experiences from using TSs as DOTS support should be shared with other institutions that are running DOTS programs in Zambia. Training of TSs and a close follow up and supervision of TSs by HWs should be ensured.

Involvement of family and friends: should be put on the daily agenda in the DOTS programs in the Copperbelt province due to the positive effects of involving family and friends.

Privacy in consultations: consultations should be arranged so they are private in order for the patients to feel comfortable to ask questions and discuss concerns and worries with the HW or TS.

Repeated information that makes sense: the information patients receive during the first consultation at the health clinic should be repeated several times during the treatment due to the fact that patients often forget the information, and the advice/information should be given, and discussed for the patients to understand the reason behind the advice/information.

Patient support groups: TB patient support groups where patients can meet and share experiences and concerns should be organized

Booklets: TB information booklets should be distributed to all patients

Further research

In this study the patients' experiences and perceptions of participating in a DOTS program has been in focus. The HWs and TSs experiences and perceptions have, however, not been explored. Further research regarding HWs and TSs level of awareness of the needs for improved communication skills and awareness of how good and poor communication can affect the patients are needed.

In this study discrimination and judgement of TB patients by friends and community members was identified, however the term stigma has not been used since the term stigma is a complex matter that would have needed more in-depth exploration. Further research related

to the connection between TB related stigma, poor treatment adherence and low TB detection rates is recommended.

The Patients' Charter for TB Care (5) has influenced the objectives of this study. Zambia has implemented the Stop TB strategy (6), and the Patients' Charter for TB Care is a part of the Stop TB strategy. However, little is known about how health institutions in Zambia are bringing the Patients' Charter for TB Care into action. Findings from this study indicated that the Patients' Charter for TB Care was not used by HWs and TSs in the daily DOTS treatment. Further studies regarding how one can implement and bring the Patients' Charter for TB Care into action are needed.

WHO emphasizes, in the revised DOTS strategy, the need for more patient-centred approaches. Several health institutions, however, seem to be hesitant to make any changes in their programs, although the changes are low-cost. Further research looking into reasons behind the institutions hesitation to change the DOTS program is needed.

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Appendix 1: Interview Guide - individual interviews

This interview guide was used as a checklist. Not all questions were asked in all individual interviews. Questions were added to the interview guide/checklist during the data collection period when new themes/topics emerged.

Interview Code:

Date:

Interviewer:

Age:	
Sex:	
Occupation:	
How many months on DOTS:	

Introduction:

1. Can you please tell me how it to live with TB?
2. Can you please tell me how being sick with TB has affected your life at home?
3. Can you please tell me if anything in your life changed after you got TB?
4. What was your reaction when you were told by the HW/doctor that you have TB?
5. What did you know about TB before you got sick?
6. How do you think you got TB?
7. How do you look after yourself when you have TB? (manage life, take care of yourself)
8. Do you have anyone that helps you? (supports you)
9. How do they help you?

Information and advice:

10. Can you please tell me about your first consultation at the Health Clinic?
11. Did you bring someone with you to the health clinic?
12. How were you received by the doctor/HW/TS?
13. What did the HW/TS ask you?
14. What questions did you ask the HW/TS?
15. Do you feel free to ask the HW/TS any questions you have in the consultation?
16. What is the reason you ask/don't ask HW/TS any questions?
17. Who do you ask if you don't ask the HW/TS?
18. What do you think is the reason for the HW/TS not to ask you more questions?

19. Did you get to choose whether to come to the clinic for medicines or to take the medicines at home?
20. How often do you meet the HW/TS?
21. Do you feel that the HWs are spending enough time with you when you come to the clinic?

Care:

22. How are you received when you come to the clinic now?
23. Can you please tell me what you and the HW or TS talk about when you meet now?
24. Do you talk in private or are there other people around?
25. Have you ever been treated really well by a HW? (Please tell the story)
26. What did the HW/TS do?
27. What was he/she doing that other HW/TS do not do?
28. How do you ever felt that you were badly treated by HW?
29. How can you tell that someone has a good heart?

Involvement of family:

30. Have the HW/TS ever visited you at your home?
 31. What did they do/say?
 32. Did the HW/TS talk to your family members?
 33. What information did they give to your family?
 34. What did you feel about the HW/TS coming to your home?
 35. What do you think is the reason they come to your home?
- If not visited by TS at home:
36. What do you think is the reason you have to come to the clinic every day/every week (in initial phase) to collect you medicine?

Motivation:

37. Can you please tell me who has helped you/motivated you the most to continue the treatment?
38. How do they motivate you?
39. What could the HW/TS do to help you more?
40. Have you ever considered stopping treatment?
41. Do you know anyone who has stopped taking medicines? What happened?

Reactions from family and friends:

42. Has anyone treated you differently after you got TB?
43. How has having TB affected your social life?

- 44. Are you moving around – going to the market, visiting friends/relatives like you used to before you got sick? (Why not?)
- 45. Who knows that you have TB? (family, neighbors, workplace)
- 46. How did they react when you told them?
- 47. Has anyone ever blamed you for getting TB?
- 48. Have you ever blamed yourself for getting TB?

Any questions from the study participant?

Note down all the questions the participant asked after the interview has formally ended.

For interviewer:

Thank the participant for his/her participation and contribution. Do a recap of the interview so the participant can verify the information.

Ask participant if he/she will give us permission to cite him/her. Remind the patient that no name, address or town will be used when presenting the data. Assure participant again that all information will be handled confidentially. Remind participant that he/she can contact us at any time if any questions.

Appendix 2: FGD guide/Group discussion guide

FGD Code:

Date:

Interviewer:

Number of participants:								
Age:								
Sex:								
Occupation:								
How many months on DOTS:								

1. Can you please tell how it is to live with TB?
2. Can you please tell me if anything in your life changed after you got TB?
3. How do you look after yourself when you have TB? (manage life, take care of yourself)
4. Do you have anyone that helps you/supports you?– How do they support you?
5. How were you received by the HW/TS the first time you came here?
6. Have you ever been treated really well by a HW? (Please tell the story)
7. How do you ever felt that you were badly treated by HW? (Please tell the story)
8. How can you tell that someone has a good heart (or not a good heart)?
9. How often do you meet the HW/TS?
10. Do you feel free to ask the HW/TS any questions you have?

Any questions from the study participants?

Note down all the questions the participants asked after the interview has formally ended.

For interviewer:

Thank the participants for their participation and contribution. Do a recap of the interview so the participants can verify the information.

Ask participants if they will give us permission to cite them. Remind the patients that no name, address or town will be used when presenting the data. Assure participants again that all information will be handled confidentially. Remind participants that they can contact us at any time if any questions.

Appendix 3: Information sheet and informed consent form

REQUEST FOR PARTICIPATION IN INTERVIEW OR FOCUS GROUP DISCUSSION

Study: Tuberculosis patients' experiences of participating in a DOTS program in the Copperbelt province of Zambia

My name is This study is a part of a master's degree program in international health at the University of Oslo, Norway.

The purpose of the study is to explore tuberculosis patient's experiences of participating in a DOTS program.

I would like to ask if you are willing to participate in a group discussion or in a individual interview. I wish to hear about your experiences as being a part of a tuberculosis treatment program. Your experiences and your opinions can be helpful in order for health personnel to understand TB patients needs, and thereby help health staff and treatment supporters to improve the way they communicate with you.

All the information that you give me will be treated with confidentiality. Your name or address will never be used in connection with the information that you give.

Your name or address will not be written on any interview notes. I will not share any details of what you tell me with others unless you are willing to. The information you give me is for the purpose of this study only. All notes and tape recordings I take during the interview or group discussion will be deleted after the study is finished.

The findings from this study will be presented in my master thesis. I will also present the findings to CHEP. The findings might also be presented in academic journals.

Participating in this study is optional. If you decide not to participate in the study, or if you at any point decide to withdraw from the study you do not have to give any reason for this, and the information you have given will be deleted. Withdrawing from the study will not have any impact on your access to- or quality of treatment.

You can say no to discuss issues you don't want to discuss during the interview without giving any reason for this. The Interview will last approximately 1 hour and a group discussion will last approximately 1 ½ hours.

You can have some time to think about this request. If you have any questions regarding the study feel free to contact the research team.

If the researcher finds it necessary to clarify issues after the interview or group discussion we might contact you again.

Consent (Statement of declaration)

I, have been informed about the content of this document and I voluntarily agree to participate in this study.

Signature:

Address:

Date:

Researcher:

Witness:

Interview code:

Contact Information:

Ms. Nina Holm

CHEP Office Kitwe

Plot No. 8, Diamond Drive, Martindale
PO BOX 23567, Kitwe, Zambia

Phone: 0212229512

Appendix 4: Ethical approval, Norway



UNIVERSITY OF OSLO
FACULTY OF MEDICINE

University Lector Ane Haaland
Institute of General Practice and Community
Medicine
University of Oslo

Regional Committee for Medical Research Ethics
Southern Norway, Section A
P.B 1130 Blindern
NO-0318 Oslo

Phone: 228 44 666

Fax: 228 50 590

E-mail: rek-2@medisin.uio.no

Homepage: www.etikkom.no

Date: 5 September 2008

Your ref.:

Our ref.: S-08418a, 2008/10450

S-08418a "Health Communication in Zambia - Tuberculosis patients' perspectives on communication with health workers" [6.2008.743]

Project manager: MA Ane Haaland, Institute of General Practice and Community Medicine, University of Oslo

M. Phil. Student Nina Holm, Section for International Health, University of Oslo

The Committee considered the application again during its meeting on 27 August 2008 on the bases of an e-mail dated 6 August 2008 with the following enclosures: a letter with answers to the comments of the committee; CV for Ane Haaland and revised letter of information with consent.

The committee accepts the explanatory response.

The committee has no objections to the revised information letters.

Decision:

The committee gives its approval to the implementation of the project.


Yours Sincerely

Kristian Hagestad
Chief County Medical Officer, Spec. of Public Health
Chairperson

Jørgen Hardang
Secretary

Copy to: M. Phil. Student Nina Holm, Section for International Health, University of Oslo

Appendix 5: Ethical approval, Zambia



TROPICAL DISEASES
Tel/Fax 615444
tdrc-ethics@tdrc.org.zm

TDRC ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

RESEARCH CENTRE
P O Box 71769
NDOLA, ZAMBIA

17th April 2009

TRC/C4/04/2009

Ms Nina Holm
Saels vei 17
5173
Norway

Dear Ms Holm

RE: Approval of Protocol: "Tuberculosis Patients' Perspectives on Communication with Workers and Treatment Supporters"

Reference is made to the above subject and your communication dated 16th April 2009.

On behalf of the Chairman of the Tropical Diseases Research Centre, I am pleased to inform you that the above mentioned protocol has been approved.


This approval is valid for the period of 17th April 2009 to 16th April 2010. You will be required to apply for a re-approval of your study at the end of this period, upon submission of a satisfactory progress report. The final report on the outcome of the study must be submitted to the Committee.

You are required to seek ethical approval from the TDRC Ethics Review Committee for any amendments to the approved protocol.


Your study number is **TDRC/ERC 1704/1208**.

The Committee wishes you every success in the execution of the study.

Yours sincerely
TROPICAL DISEASES RESEARCH CENTRE



Dr Gershom Chongwe
SECRETARY – TDRC ETHICS REVIEW COMMITTEE



cc : STC Secretary

Appendix 6: Presentation of LHL and CHEP

LHL:

LHL - The Norwegian Heart and Lung Patient Organization - is a nationwide interest organization of people with heart and lung disease. The organization was founded in 1943 by TB patients. LHL is today one of the leading patient organizations in Norway.

LHL's Program of Principles entitled «Solidarity beyond Frontiers» is the basis of LHL's fight against tuberculosis. LHL is involved in this area as an interest organization for people contracting tuberculosis. To LHL the fight against tuberculosis is a global fight which includes work in Norway and in the poorest parts of the world. Zambia is one of the 9 countries where LHL has put in strong efforts against TB and HIV/AIDS working with local partner organizations, institutions and universities (70).

CHEP:

The Copperbelt Health Education Project (CHEP) in Zambia is a non-governmental organization with company limited by guarantee status. CHEP started out as a health education project, but over time the organization became registered as an independent organisation dedicated to implement HIV/AIDS prevention and impact mitigation activities in the Copperbelt communities. CHEP's mission is to help communities in Zambia develop knowledge, values, and life skills that enable creativity, responsibility and healthy life styles through sub-granting and capacity building of local partners (71).